

healthdata.be

Centralised ICT support for registries and trials in Belgium

2017.11.28, KCE Trial symposium



CONTEXT

Inventaire des bases de données de soins de santé

KCE reports vol. 30B



“Belgium has a lot of healthcare data, but:

- Dispersion of data sources
- Accessibility problems : no central inventory, neither a central contact for retrieval of information
- Few available data quality plans (relevance, accuracy, completeness, consistency, coherence, timeliness).”

“The problem of the Unique Personal Identifier (UPI) or pseudonym (UPP):

- Legal issues
- Problems with linkage of the data
- Longitudinal analyses frequently impossible”

“Gaps in (public domain) data:

- Primary care
- Trajectories of healthcare
- Non compulsory health insurance
- Few data for nursing and rest homes RVT-ROB
- Few useful data on psychiatry mental healthcare
- HC Technology
- Non reimbursed consumption”



AP1 >

GMD - EMD => Samen



AP2 >

Ziekenhuis-EPD



AP3 >

Medicatieschema



AP4 >

Elektronisch voorschrift



AP5 >

Gegevens delen via het systeem hubs & metahub voor algemene en universitaire ziekenhuizen



AP6 >

Delen om samen te werken



AP7 >

Psychiatrische en andere instellingen en het systeem hubs & metahub



AP8 >

Invoeren van een uniform evaluatie-instrument (BelRAI)



AP9 >

Incentives voor Gebruik



AP10 >

Toegang tot de gegevens door de patiënt (PHR)



AP11 >

Communicatie



AP12 >

Opleiding en ICT-ondersteuning van zorgverstrekkers



AP13 >

Standaarden en terminologiebeleid



AP14 >

MyCareNet



AP15 >

Administratieve vereenvoudiging



AP16 >

Traceerbaarheid van de implantaten en van de geneesmiddelen



AP17 >

Veralgemeend gebruik van de eHealthBox en gegevens van zorgverstrekkers beschikbaar in CoBRHA



AP18 >

Inventarisatie en consolidatie van registers



AP19 >

Mobile Health



AP20 >

Governance, roll out en monitoring e-Gezondheid



“René, listen very carefully,
I shall say this **only once**”

“**Only once**” = key principle of Action plan eHealth 2013-2018

- a) data capture from primary (operational) sources of health care actors!
- b) re-use of previously collected data!

SCIENTIFIC DATA

Box 2 | The FAIR Guiding Principles

To be Findable:

- F1. (meta)data are assigned a globally unique and persistent identifier
- F2. data are described with rich metadata (defined by R1 below)
- F3. metadata clearly and explicitly include the identifier of the data it describes
- F4. (meta)data are registered or indexed in a searchable resource

To be Accessible:

- A1. (meta)data are retrievable by their identifier using a standardized communications protocol
 - A1.1 the protocol is open, free, and universally implementable
 - A1.2 the protocol allows for an authentication and authorization procedure, where necessary
- A2. metadata are accessible, even when the data are no longer available

To be Interoperable

- I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
- I2. (meta)data use vocabularies that follow FAIR principles
- I3. (meta)data include qualified references to other (meta)data

To be Reusable:

- R1. (meta)data are richly described with a plurality of accurate and relevant attributes
 - R1.1. (meta)data are released with a clear and accessible data usage license
 - R1.2. (meta)data are associated with detailed provenance
 - R1.3. (meta)data meet domain-relevant community standards

community after the data publication process. Unfortunately, the existing digital ecosystem

1

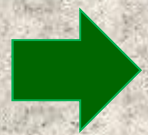
technical implementation (free & open)

information architecture (independent from technology)

technical service desk

set of business processes



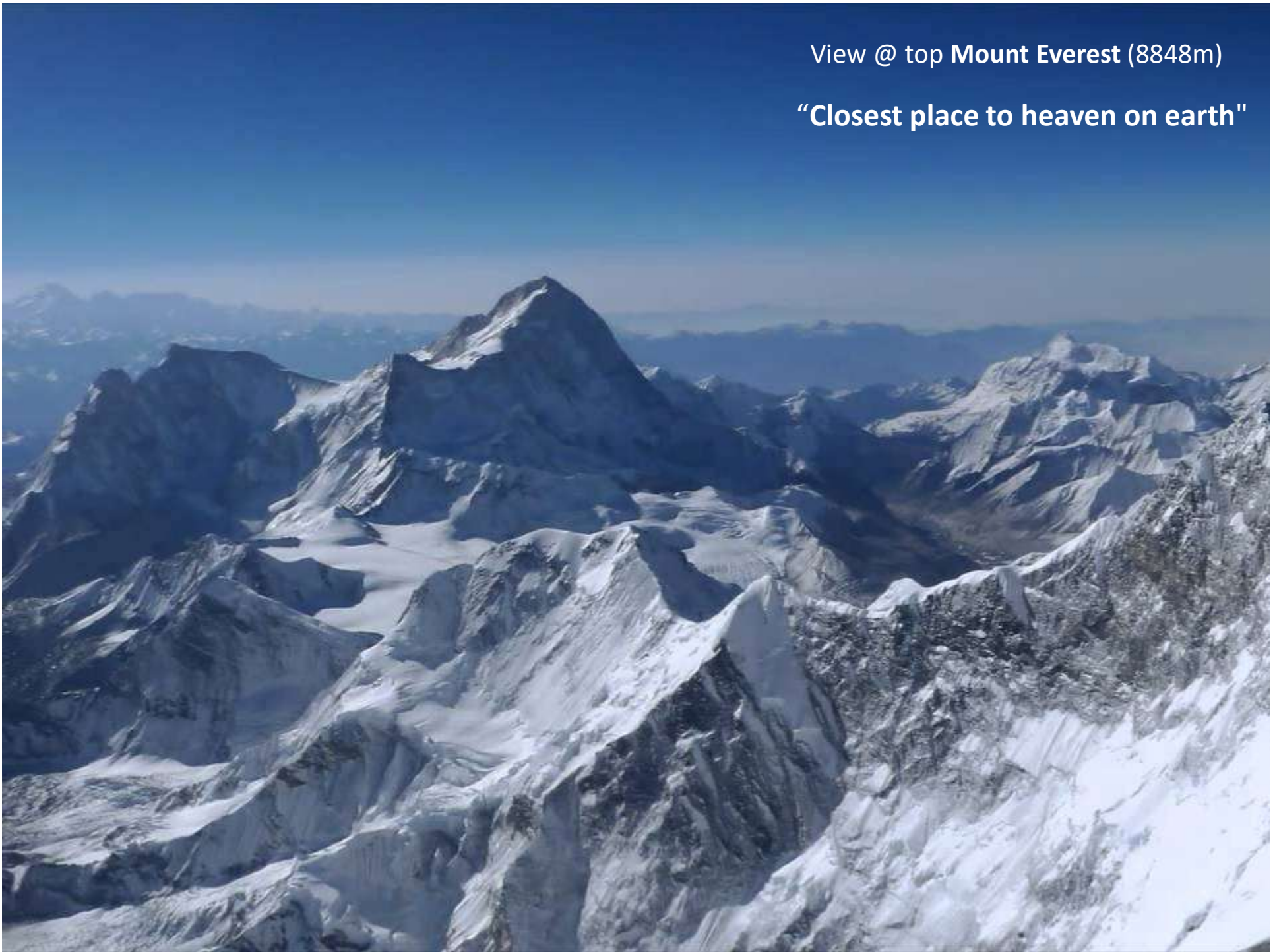


Less administrative burden & higher efficiency
= more time for patient ► higher quality of care
= more time for research ► higher quality of research
= lower costs

FINISH

View @ top **Mount Everest** (8848m)

"Closest place to heaven on earth"



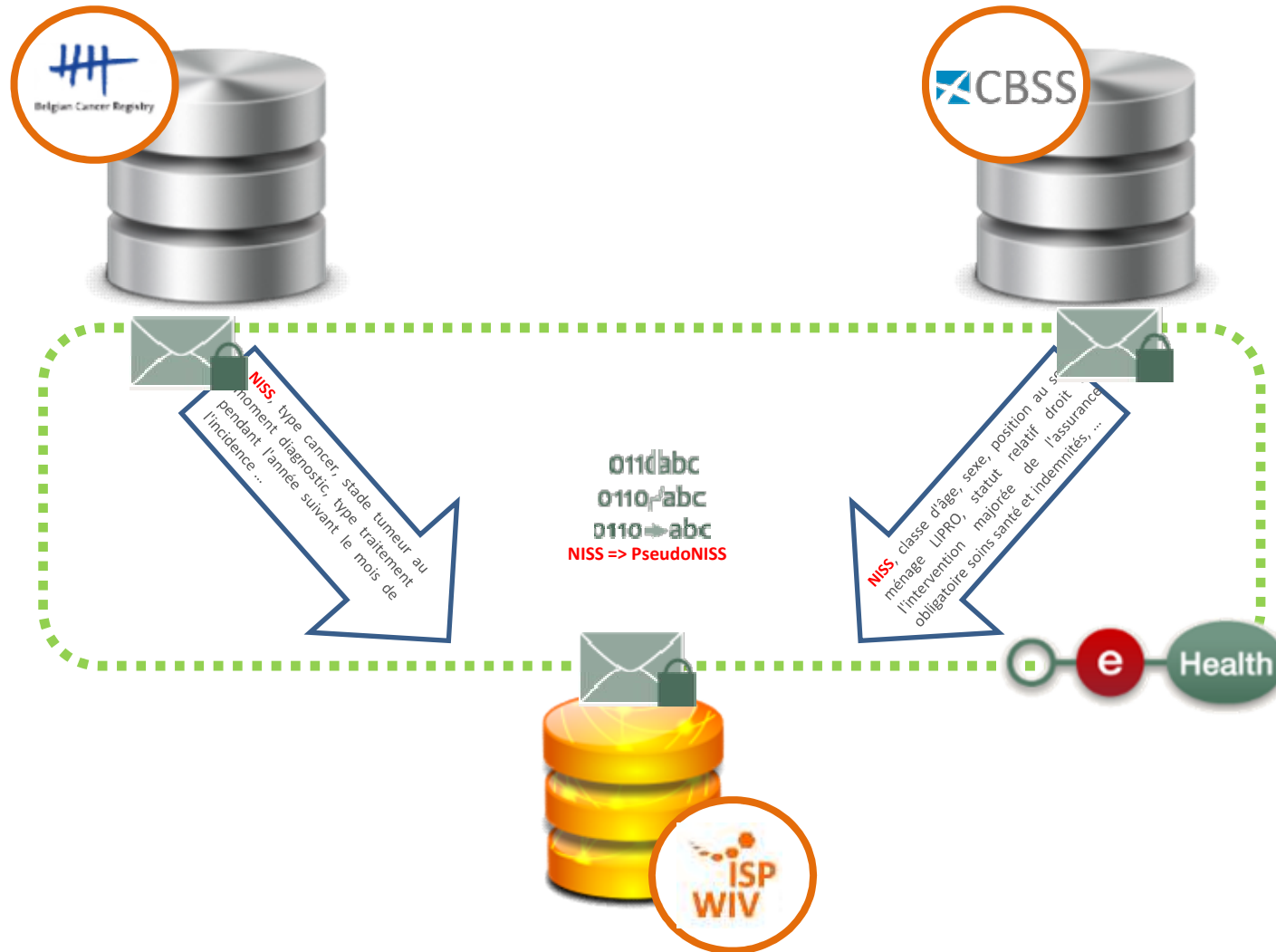


TECHNICAL ARCHITECTURE

Data collection at the source: only if necessary!

Future: increased used of “linked data”

« Etude de l'évolution position socio-économique de travailleurs belges atteints de cancer. »



Healthdata.be

Technical
description of each
data collection

isp
wiv healthdata.be

Use of National
Registry Number
as ID

ONLINE
CATALOGUE

0110abc
0110/abc
0110⇒abc

HD4DP

HD4RES

DATAWAREHOUSE (SAS)

HEALTHSTAT

0
Registration
in Primary
System

1
Data
Captation

2
Secure Data
Transfer &
encoding of
IDs

3
Data
Monitoring

Annotation
& Correction
Request

4
Data
Validation

5
Data
Storage

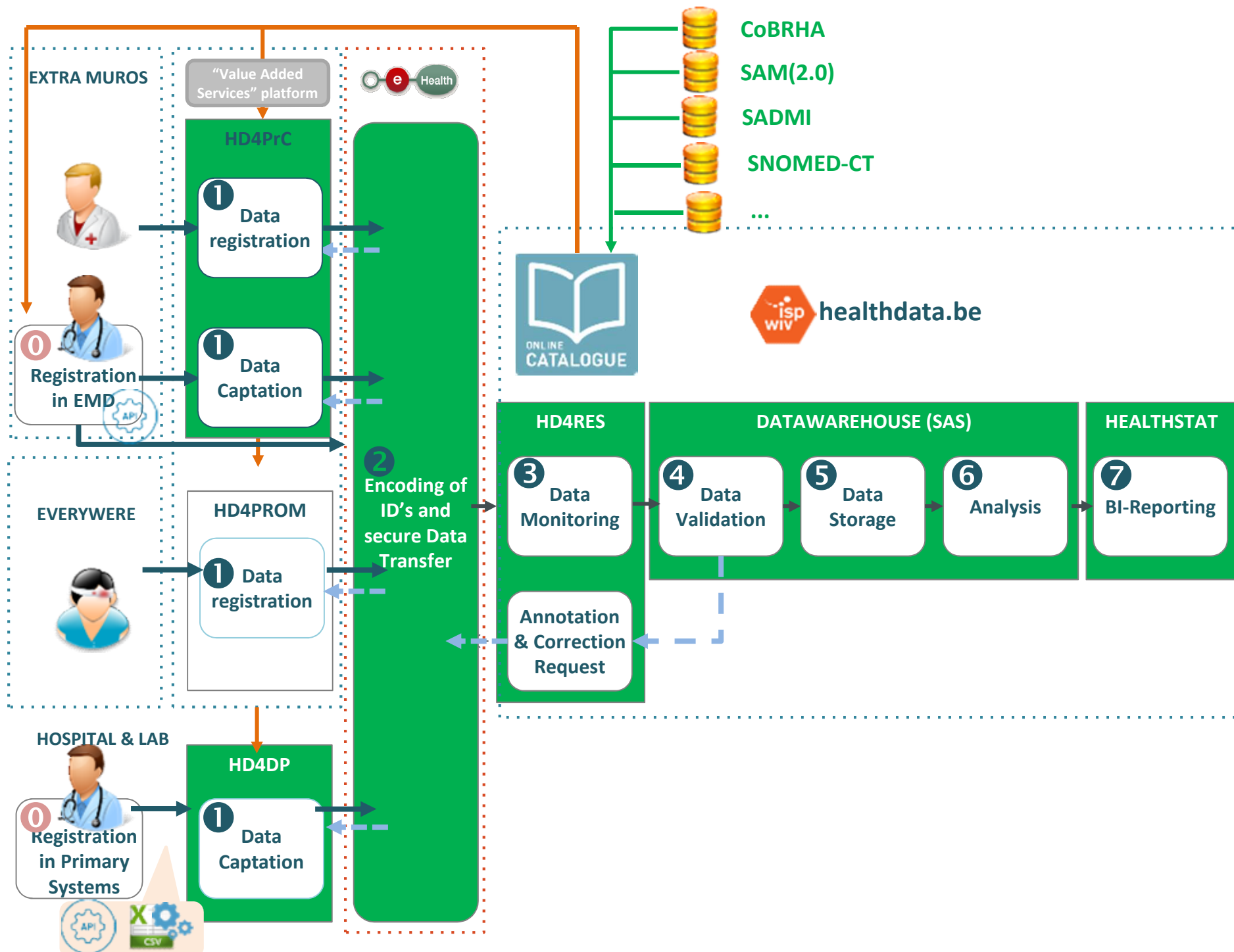
6
Analysis

7
BI-Reporting

All manual input remains available
(structured and coded, according to
[inter]national standard, based on
CBBs) in local database of DP:

- Import in future upgrade of
EPD/LIMS;
- Re-Use for internal BI & QI

Trusted Third Party
for encryption and
pseudonymization



Installation Complete



Installation is complete. You need to restart the computer in order to use the new installation.

[Restart Now](#)



hospitals
100% (of 117)



Lab genetics
100% (of 9)



Lab Ana Path
92% (of 87)



Lab Clin Bio
88% (of 150)



GP's
69% (of 11299)

ispwiv

healthdata.be
data we care for

Data Collections

Final

Amputation - Reimbursement of implants that allow the fixation of an external prosthesis
BCFR - Belgian Cystic Fibrosis Registry
BCFRecode - Recoding identifiers for BCFR
BCR - Belgian Cancer Registry
BEWSD - Belgian Early Warning System for Drugs
BNMDR - Belgian Neuromuscular Disease Registry
CRRD - Central Registry for Rare Diseases
Epilabo - Sentinel Laboratories Infection Diseases
HCV - HCV
HIV_Cohort - HIV_Cohort
HIV_Incidence - HIV Incidence
HIV_VL - HIV Viral Loads
IQECAD - Initiative for Quality Improvement and Epidemiology in Children and Adolescents with Diabetes
IQECAD_Recode - Recoding identifiers for IQECAD
IQEDFoot - Initiative for Quality improvement and Epidemiology in Multidisciplinary Diabetic Foot Clinics



DCD's Final: n = 27

DCD's draft: n= 12

Data Collection Definitions (DCD's): list view

Data Collections

← → ↻ ⌂ Veilig <https://www.healthdata.be/dcd/#/collection/213>

Collections / HCV



healthdata.be
data we care for



HCV (HCV)

version: v1.0start date: 14/10/2016

status: inactive

Unique ID: patient ID and reimbursement approval date

[How to interpret this data collection definition?](#)

Full View

CSV Column Names

Validation rules

Reference Lists ▾

Computed expressions

Additional information

CSV extract

1 Patient details

National registry ID

patient identifier

Technical specs

CSV column name:patient_id

Required:true

Clinical building block mapping (indicative only)

Concept:be.en.hd.Patient

Data element:PatientIdentificationNumber

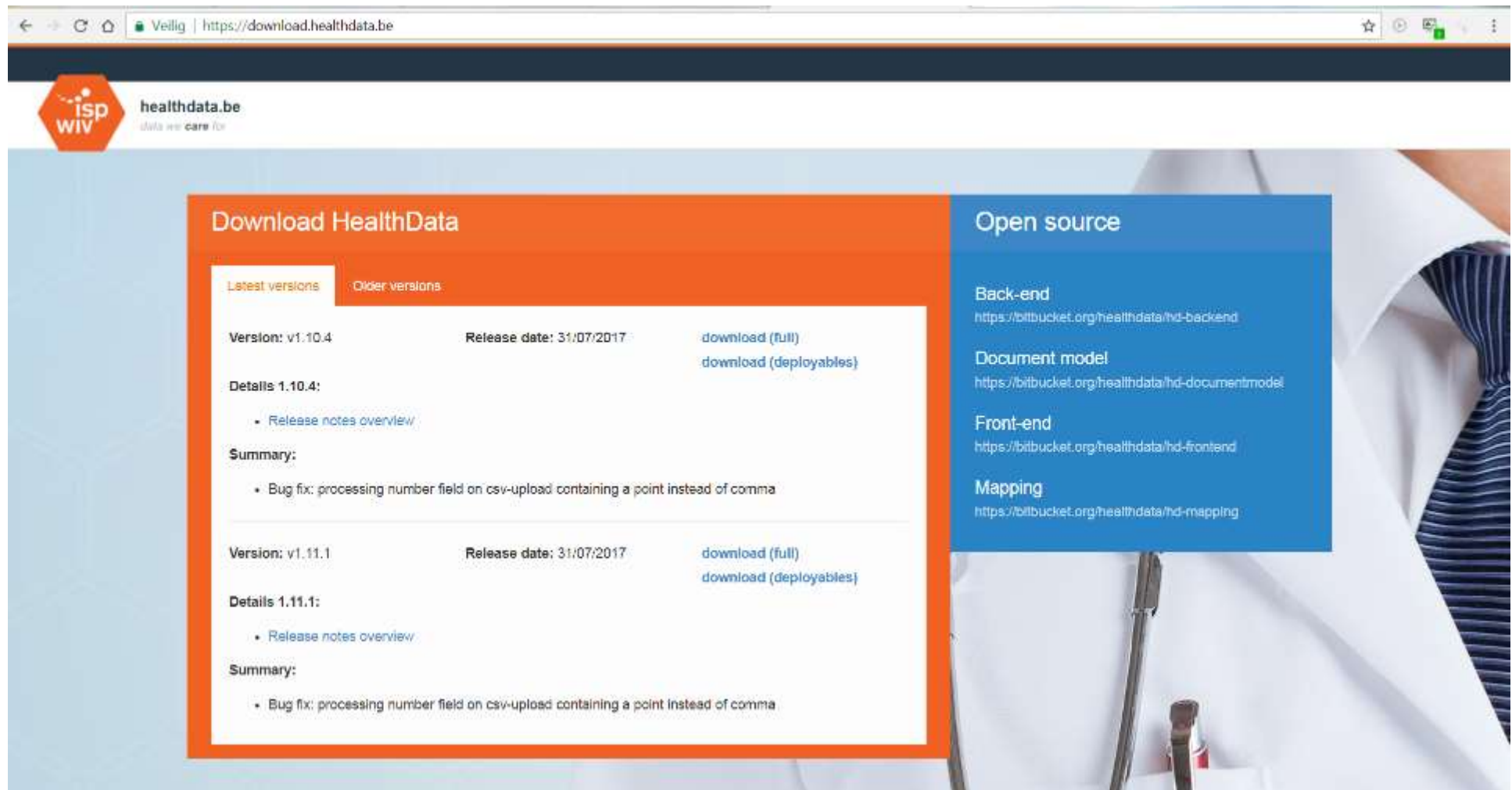
Validation

Internal patient ID

text

Data Collection Definitions (DCD's): full description

HD software is publicly available



The screenshot shows a web browser window with the address bar displaying "https://download.healthdata.be". The page features the "isp wiv" logo and the text "healthdata.be data we care for". The main content is divided into two sections: "Download HealthData" and "Open source".

Download HealthData

Latest versions | Older versions

Version	Release date	download (full)	download (deployables)
v1.10.4	31/07/2017	download (full)	download (deployables)
Details 1.10.4:			
Release notes overview			
Summary:			
Bug fix: processing number field on csv-upload containing a point instead of comma			
v1.11.1	31/07/2017	download (full)	download (deployables)
Details 1.11.1:			
Release notes overview			
Summary:			
Bug fix: processing number field on csv-upload containing a point instead of comma			

Open source

Back-end
<https://bitbucket.org/healthdata/hd-backend>

Document model
<https://bitbucket.org/healthdata/hd-documentmodel>

Front-end
<https://bitbucket.org/healthdata/hd-frontend>

Mapping
<https://bitbucket.org/healthdata/hd-mapping>

Demo environment of HD software available

The screenshot shows a web browser window with the address bar displaying "https://demo.healthdata.be". The browser's address bar also shows "Veilig" (Safe) and "https://demo.healthdata.be". The browser's tabs include "Archive", "acc.HD4DP", "Aanvraagformulieren", "BP Dashboard - Health", and "DCD - Agile Board - H". The website's header features the "isp wiv" logo and the text "healthdata.be data we care for". The main content area has a light blue background with a white geometric pattern. A large white text block reads: "Welcome to the demo page of healthdata.be, where you can access demo versions of the healthdata.be software for data providers and researchers." Below this, there are two columns. The left column has an orange background and is titled "HD4DP for data providers". It contains the text: "The HD4DP software is used by the data providers (medical professionals in hospitals, laboratories, individual practices, ...) for data collection. This software is installed locally at the data provider. This demo environment is an online, production-like version and allows you to get familiar with the user interface of the data collection software. You can create registrations and submit these to the HD4RES demo environment. It is also possible to test the CSV upload, but it is not possible to test the automatic CSV upload or API." The right column has a blue background and is titled "HD4RES for researchers". It contains the text: "The HD4RES software is used by the researchers for follow-up collections and for managing the data collection definitions (i.e. registry). The demo environment allows the researchers to get familiar with their data collection follow-up software. It is possible to create registrations that were submitted with the HD4DP demo environment and to test these registrations. The log-in details for the HD4RES demo environment are: user: demo, password: demo1234567890".

Veilig | https://demo.healthdata.be

Archive | acc.HD4DP | Aanvraagformulieren | BP Dashboard - Health | DCD - Agile Board - H

isp wiv healthdata.be
data we care for

Welcome to the demo page of healthdata.be,
where you can access demo versions of the
healthdata.be software for data providers and
researchers.

HD4DP

for data providers

The HD4DP software is used by the data providers (medical professionals in hospitals, laboratories, individual practices, ...) for data collection. This software is installed locally at the data provider. This demo environment is an online, production-like version and allows you to get familiar with the user interface of the data collection software. You can create registrations and submit these to the HD4RES demo environment. It is also possible to test the CSV upload, but it is not possible to test the automatic CSV upload or API.

HD4RES

for researchers

The HD4RES software is used by the researchers for follow-up collections and for managing the data collection definitions (i.e. registry). The demo environment allows the researchers to get familiar with their data collection follow-up software. It is possible to create registrations that were submitted with the HD4DP demo environment and to test these registrations. The log-in details for the HD4RES demo environment are: user: demo, password: demo1234567890

Demo environment of HD software available

← → ↻ 🏠 Veilig | https://hd4dp-demo.healthdata.be/#/document/new/331?groupId=208

HD4DP Deelname Datacollectie Rapportering Gids Instellingen Help ▾ Guest Guest ▾

Inhoudstafel Info Terug Opslaan Verstuur Validatie 12 Commentaren

NGS v1.0
Inhoudstafel
1 Identificatiecode van de patiënt
2 Caregiver
3 Medische gegevens
4 Laboratory data
5 Attachments

Samenvatting

1 - Identificatiecode van de patiënt

Rijksregisternummer van de patiënt *

Intern patient ID

Naam *

Voornaam *

Geboortedatum *

dd/mm/yyyy

Geslacht *

☒ Vrouw
☐ Man
☐ Onbekend

Overleden ?

Voortgang

Validatiefouten (x)
Geen validatiefouten

Verplichte velden (*) 12

- Rijksregisternummer van de patiënt: verplicht veld
- Naam: verplicht veld
- Voornaam: verplicht veld
- Geboortedatum: verplicht veld
- Geslacht: verplicht veld
- Woonplaats: verplicht veld
- Land van verblijf: verplicht veld
- Incidence date: verplicht veld
- Primary tumor localization: verplicht veld
- Stadium: verplicht veld
- Sample type on which the test was executed: verplicht veld
- VCF file: verplicht veld

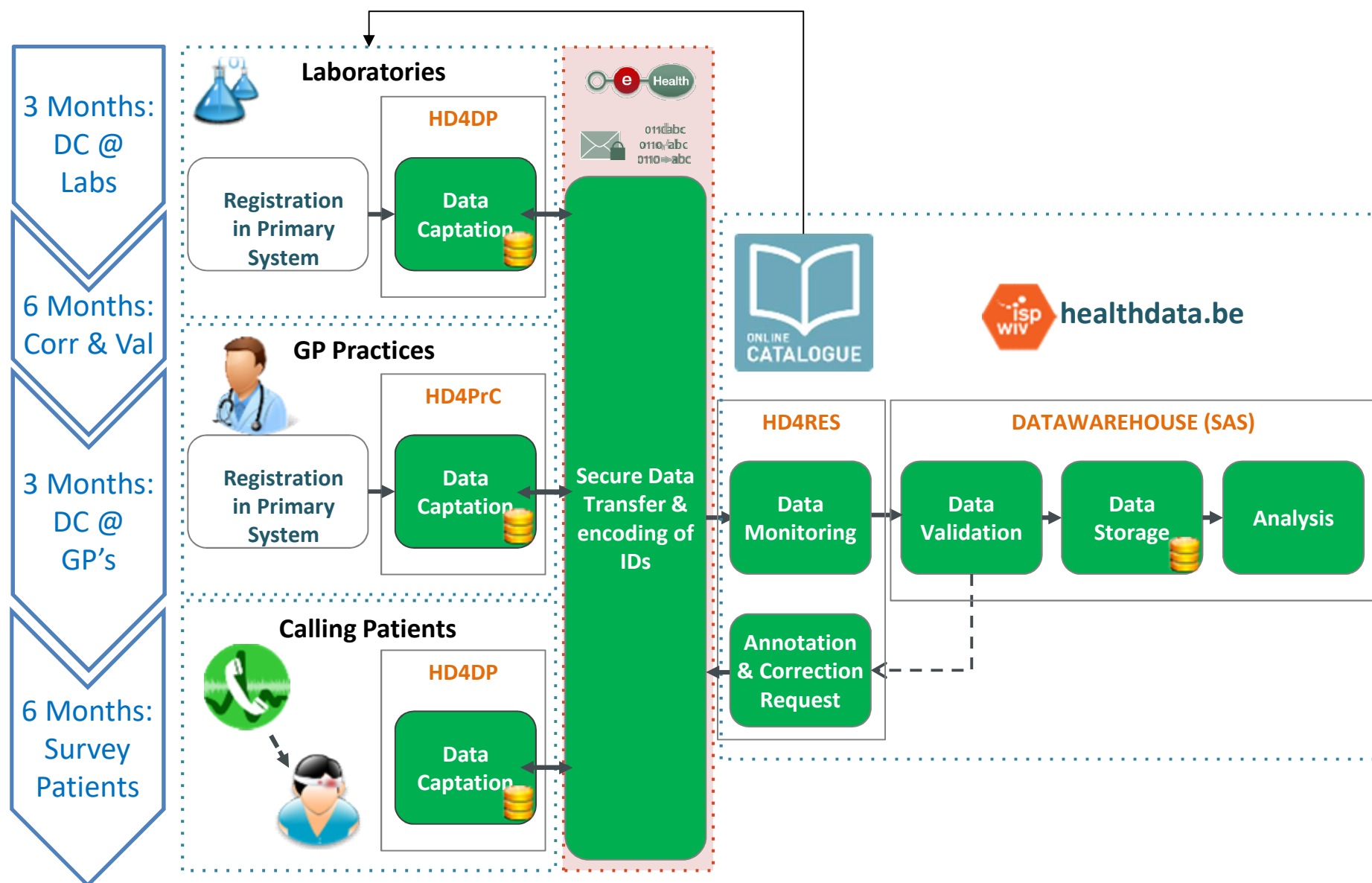
Validatiewaarschuwingen (!)
Geen validatiewaarschuwingen



**Projects in
production
N = 27**

**“To do”
N > 100**

KCE funded trial on randomized evidence-based order sets



REPORTING

Your portal to Belgian health statistics



Nieuws [lees meer](#)

- 14/03/2017** Feedback reports of project "Belgian Neuromuscular Disease Registry" (BNMDR) are available for participating health care organizations and g ...
- 10/03/2017** Feedback reports of project Belgian Treatment Demand Indicator Registry (BTDIR) are available for participating health care organizations an ...
- 10/03/2017** Launch of healthstat.be, the data visualization platform of the Healthdata.be project.
- 14/02/2017** Communication to health care organizations: responsible for eHealth User Access Management can start appointing access rights in UMAN applic ...

Over healthstat.be

Healthstat.be is het datavisualisatie platform van [Healthdata.be](#), een project dat deel uitmaakt van het nationaal [Actieplan eGezondheid 2013-2018](#). Hier publiceren de onderzoekers tabellen, figuren en kaarten die zij maakten op basis van gegevens die zij bij de Belgische ziekenhuizen, laboratoria, huisartsen, en patiënten hebben verzameld. Met deze rapporten willen de onderzoekers aan de betrokken zorgverleners, zorginstellingen, patiënten, overheden en het brede publiek een up-to-date inzicht geven over het voorkomen van bepaalde ziekten, hun oorzaak en impact, alsook de doeltreffendheid van hun behandeling.

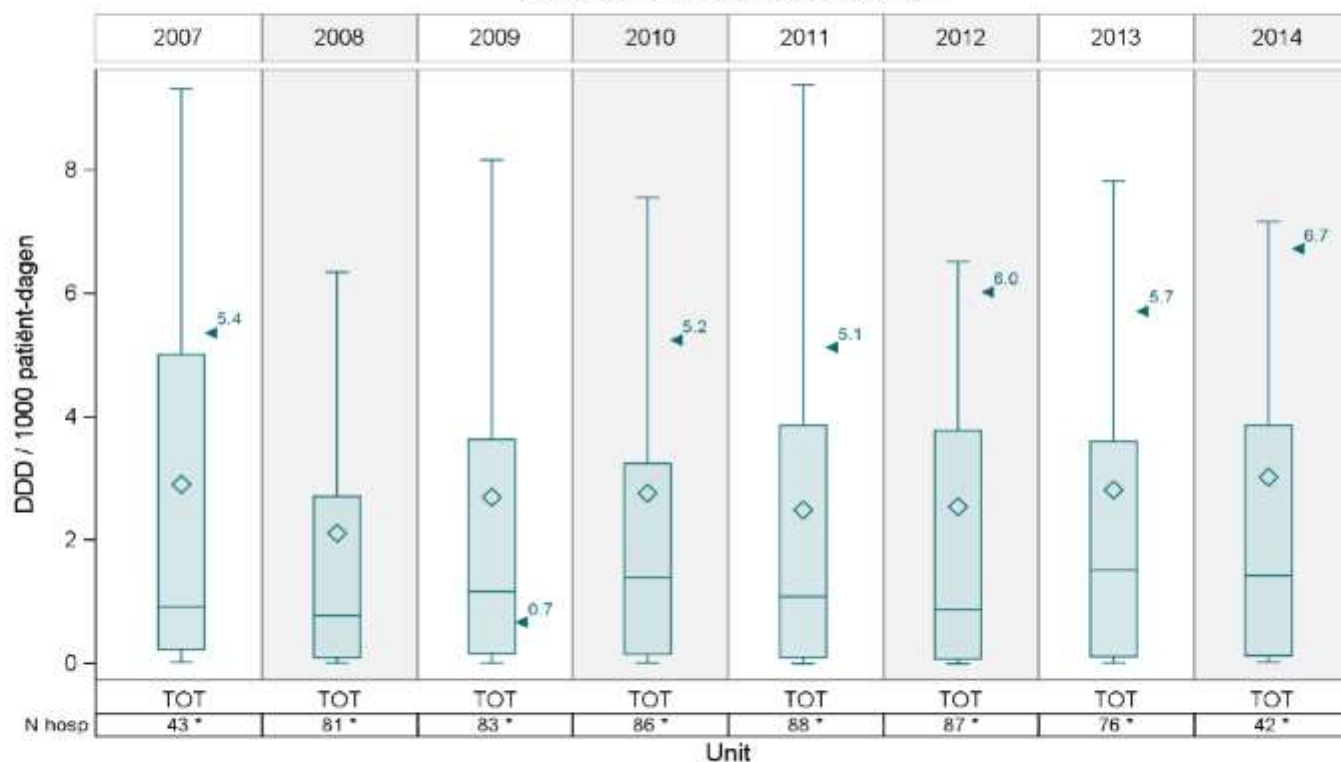
Roadmap

Op Healthstat.be zullen tabellen, figuren en kaarten voor vele beleidsondersteunende wetenschappelijke projecten gepubliceerd worden. Het moment waarop de datavisualisaties voor een specifiek project gepubliceerd zullen worden, is ondermeer afhankelijk van de hervorming van de gegevensverzameling van dat project. De [planning](#) daarvan kan u op de website van het healthdata.be-project vinden.

In een eerste fase zullen voornamelijk zogenaamde private datavisualisaties beschikbaar zijn. Deze kunnen enkel door de betrokken zorgverleners, zorginstellingen en overheden geconsulteerd worden. Hiervoor moeten zij inloggen met hun identiteitskaart. In de

data tonen als: **Grafiek** Tabel

Benchmark: alle ziekenhuizen van België
Product: A07AA - Intestinal antibiotics



◀ eigen gebruik * bevat uitschieters (niet weergegeven in de grafiek)
TOT: total for hospital

Q&A



www.healthdata.be



healthdata@wiv-isp.be



[healthdata be](https://www.linkedin.com/company/healthdata-be)



[@healthdatabe](https://twitter.com/healthdatabe)

