



Minister van Sociale Zaken en Volksgezondheid

MAGGIE DE BLOCK

Data for Better Health (Reflectie & Stavaza)

Etienne Maerien
18 maart, 2019





Minister van Sociale Zaken en Volksgezondheid

MAGGIE DE BLOCK

DIGITAL Belgium



“Digital Belgium” is the action plan, which outlines the digital long-term vision for our country and translates this into clear ambitions. On the basis of five clear, specific priorities we would like to put Belgium more firmly on the digital map.

5 priorities

DIGITAL
INFRASTRUCTURE

DIGITAL CONFIDENCE
AND DIGITAL SECURITY

DIGITAL GOVERNMENT

DIGITAL ECONOMY

DIGITAL SKILLS AND JOBS



Maggie De Block @Maggie_DeBlock · 14 u

True! And do not worry: we aren't afraid. On the contrary. By developing a coherent policy on the use of [#bigdata](#) in [#healthcare](#), we want to improve the outcome for our patients! [@healthdatabe](#) [@agoria](#) [@BEMEDTECHTWEET](#) [@sciensano](#)

Gilbert Bejjani @drbejj

Power of [#bigdata](#) ... we should not be afraid and try to get the best of it [#clinical](#) assistance , and better quality [@Maggie_DeBlock](#) [@PedroFacon](#) [@numerikare](#) [twitter.com/karolinskaunsj...](#)

Tweet vertalen



1



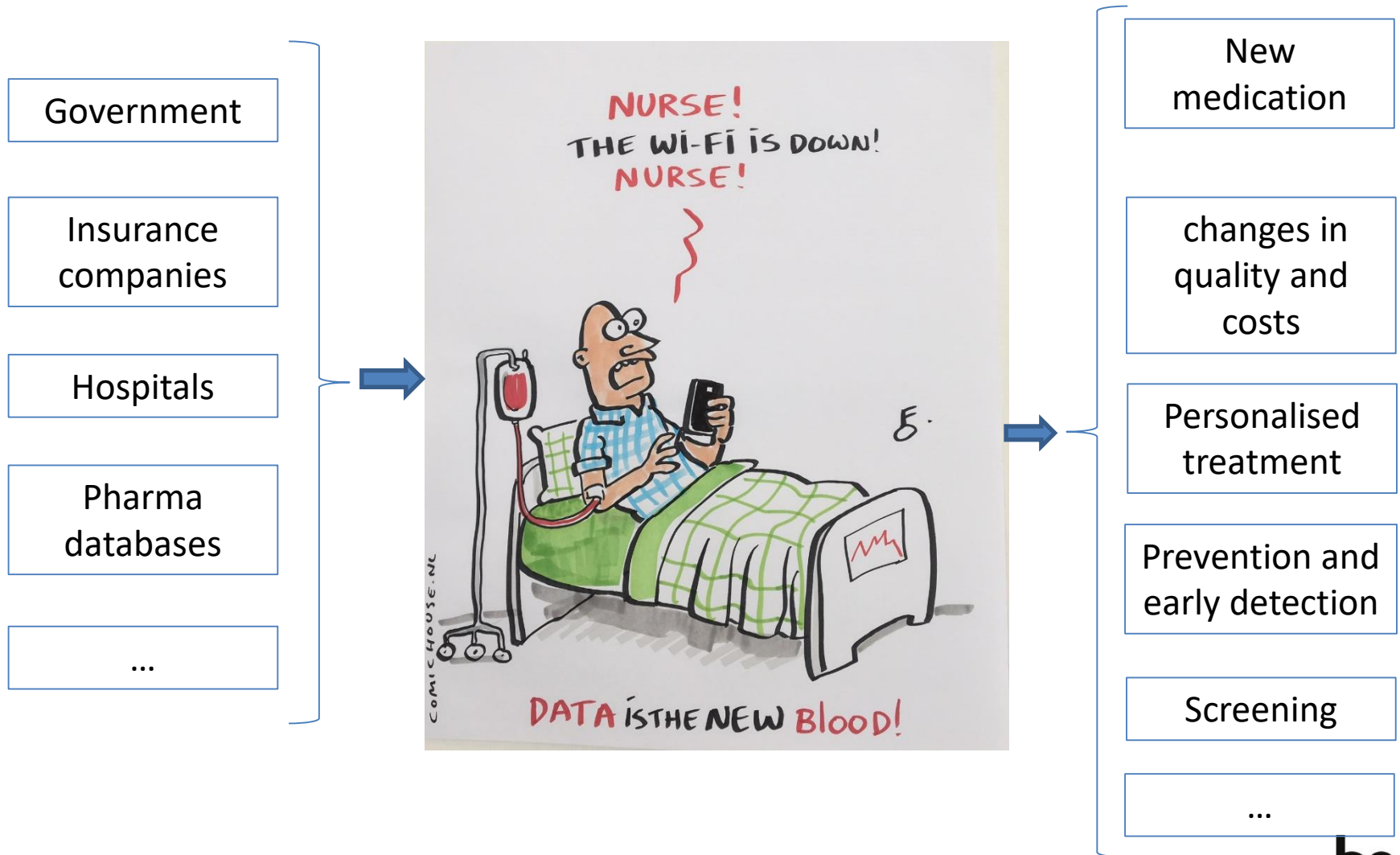
6



17



Data is the new gold/oil/blood



Fact-checking ...

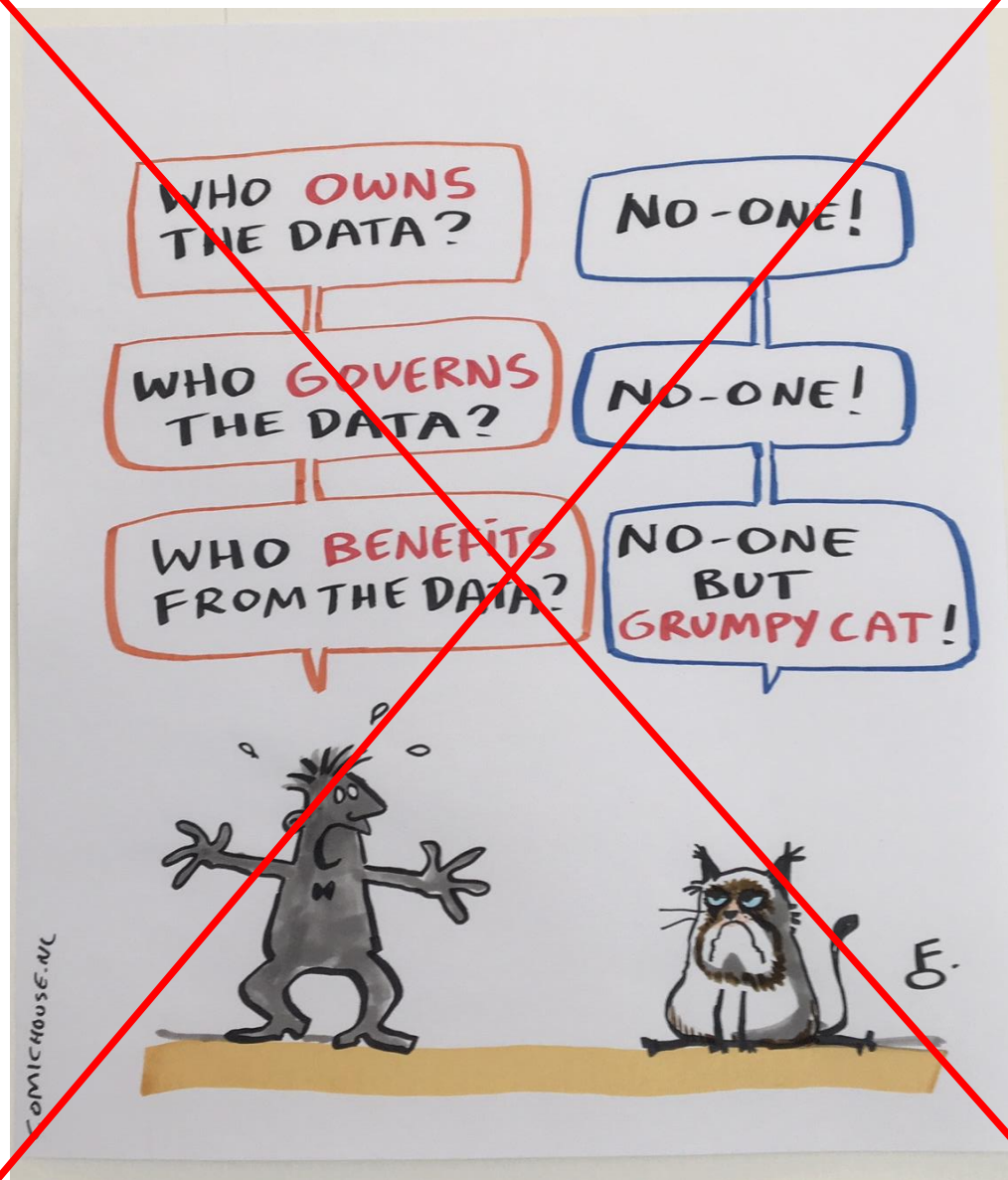
Fact: A lot of health data is created on behalf of the Belgian governments

Fact: Many profit and non-profit actors are interested in using this data

Fact: Interested parties often do not know how to apply for access to and re-use of this data

Fact: Responsible managers of the data often have no idea what others can do with this data

Fact: Today these data are not readily available. Many efforts are needed to make this data accessible. Priority setting is necessary.



An outcome of the project

Minister M. De Block - Ontwerp van beleidsnota gezondheidsbeleid – 2018 - projet de note politique 'politique de santé'

**ALGEMENE
BELEIDSNOTA**

2018

GEZONDHEIDSBELEID

How to link and
anonymise?

**NOTE POLITIQUE
GENERALE**

2018

POLITIQUE DE SANTE

What are the
guidelines when
developing new
applications?

How to structure and
organise a lean and
efficient governance
organ?

What are the goals and
what/how to prioritise?

History: slow start

2010



History: slow start

2010



2012

Round table meetings eHealth



Many issues related to “registries”

History: slow start

2010

2012

2015



Round table meetings eHealth

Action plan 2015-2018



Action Point 18: inventory of all registries

History: slow start

2010

2012

2015

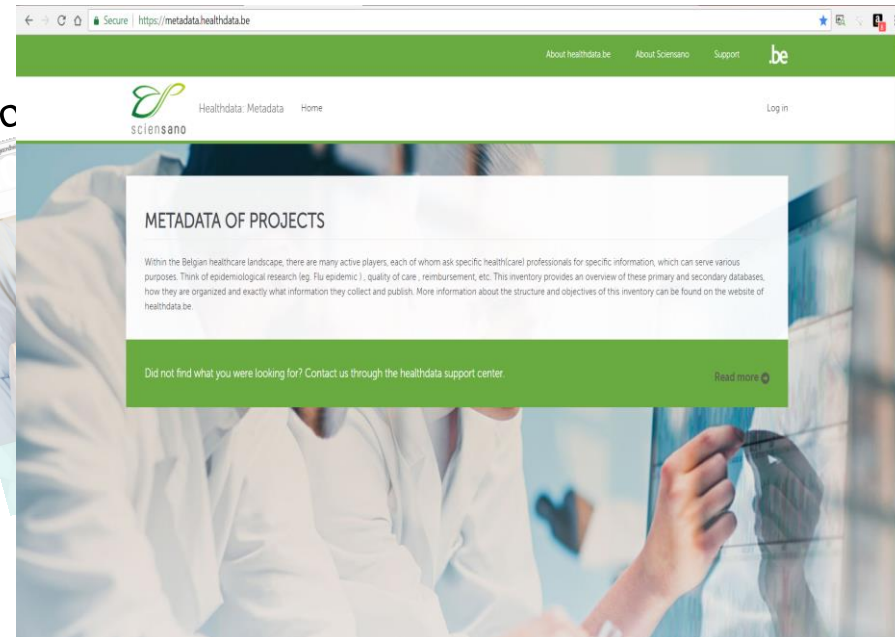
2017



Round table meetings eHealth



Action plan 2015-2018

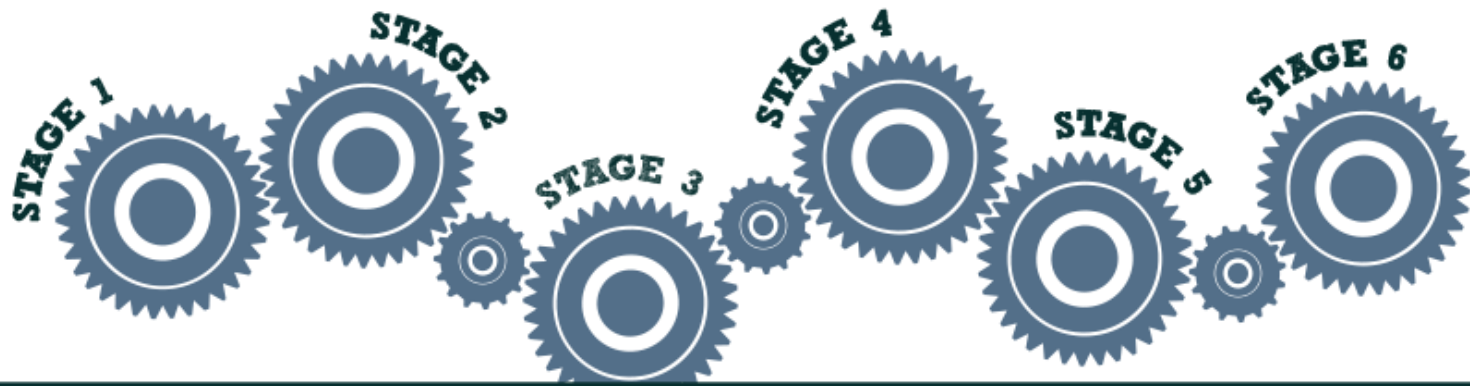


Action Point 18: **inventory Available**
.be

Next 12 months: acceleration

Sept 2017

“Big Data” / GIGOB: The roadmap



of the "Integrated Health Data Access Policy" initiative

Next 12 months: acceleration

Sept 2017

Feb 2018



The Kick-off

1 February
2018



Next 12 months: acceleration

Sept 2017

Feb 2018

Sum 2018



Next 12 months: acceleration

Sept 2017

Febr 2018

Sumr 2018

Sept 2018

"Big Data" / GIGOB: The



Minister van Sociale Zaken

Where ? @DigiTyser
Audience ? All
Program ?

Kick-off meeting

- 1 Presentation "data for better health", by Dr. Maggie De Block, Minister Volksgezondheid en Sociale Zaken
- 7 Presentation "Request portal" "data for better health"

Eventbrite

Request portal

First release in production: <https://requests.healthdata.be>

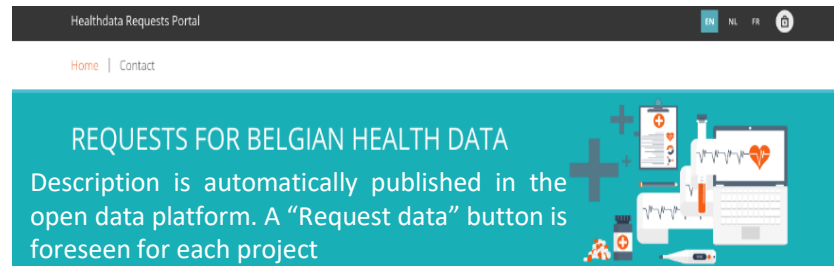
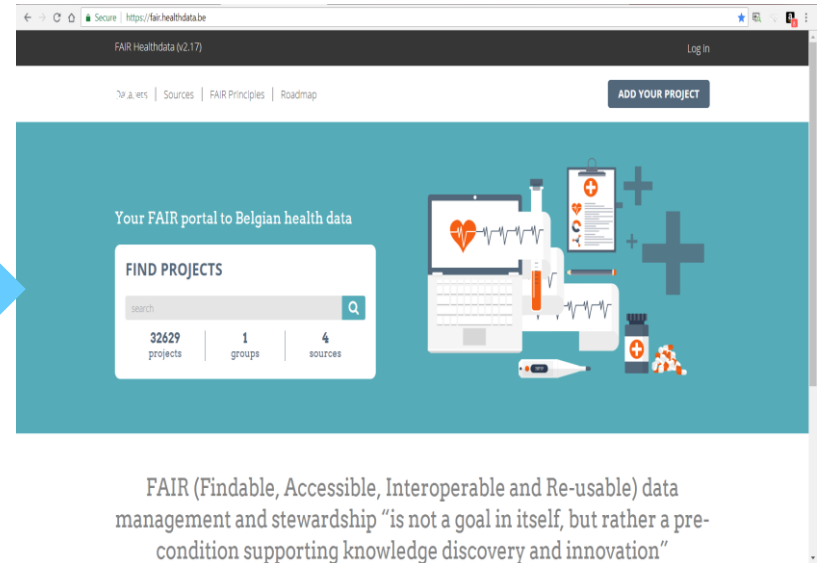
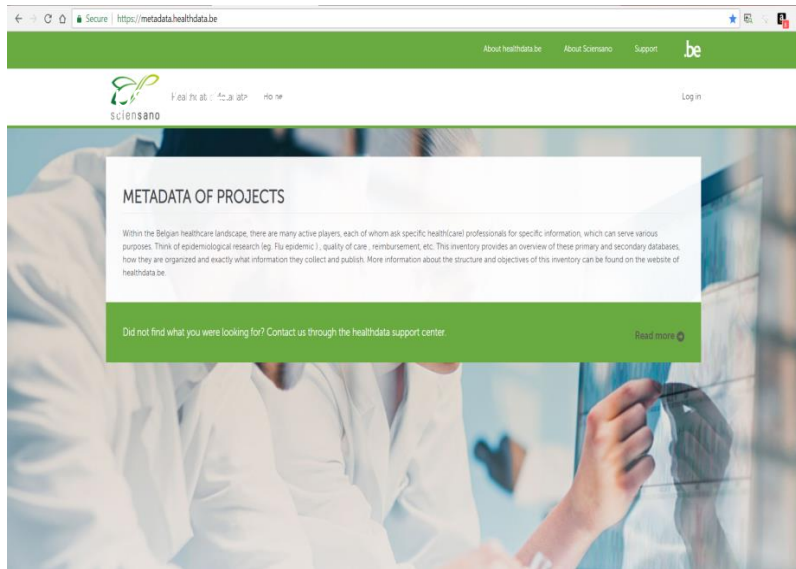
Aims to provide a single point for requests for this data

Phased approach: First phase : given the need for priorities, first focus is the identification of the demand (both in number of requests and type of proposed use). Based on this information, government and data managers will be able to set priorities (and probably find “quick wins”) in making this data FAIR.

Workshops with data managers and hackathons with applicants will identify the existing impediments for a FAIR use of this data, and will help to formulate, test and implement solutions for these impediments

Solutions and priorities will be included in the **Policy note** of the federal minister of Public Health.

From Metadata to request portal



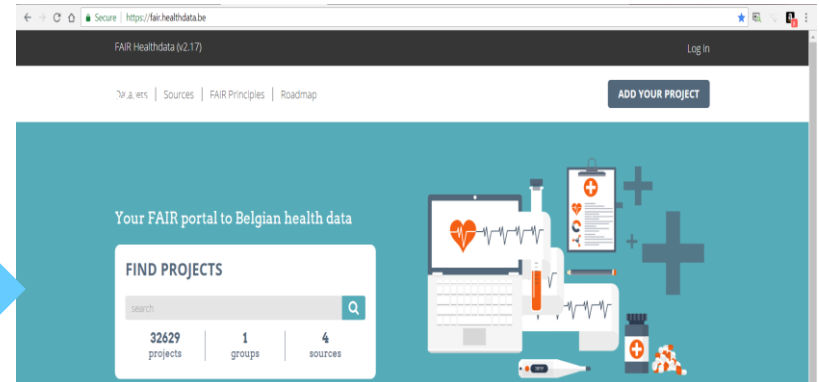
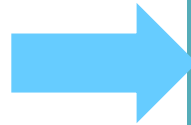
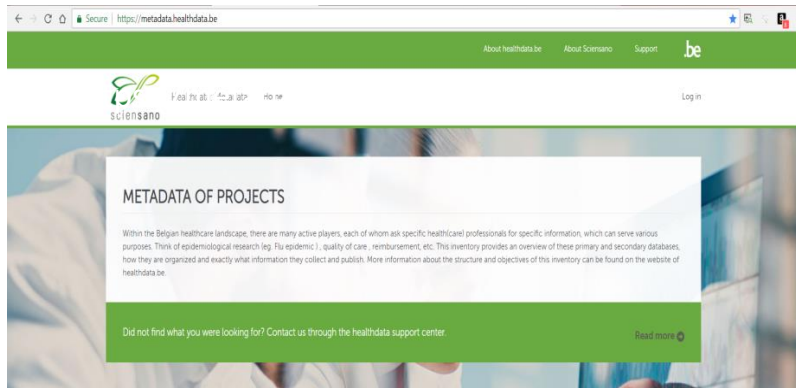
This request portal is part of the #dataforbetterhealth initiative. The initiative "#dataforbetterhealth" aims to identify the existing impediments for a FAIR data policy in public health and to formulate, test and implement solutions for these impediments in order to achieve an integrated data access policy. These solutions must be technically, semantically, economically and legally sustainable. In addition, a widely supported governance model needs to be elaborated.

It can be expected that an integrated data access policy will lead to better support for scientific research, a more effective development of medicines and medical devices, improved patient care, improved and support for clinical trials, support for personalized care, support for prevention, patient centered care, and lower medical expenses...

In the first stage of the initiative, the request portal will identify and quantify the need for and use cases with the data sets created with governmental support. This will help to set priorities in making available open and FAIR data sets. The requests are immediately forwarded to the owners and hosts of the requested data set. They will treat your request with care. In a later stage, a workshop "meet the data manager" will be organized. Applicants will have the opportunity to meet the data manager of the requested data set and will receive feedback on the request.

The request portal is not only for researchers. In fact, the "#dataforbetterhealth" initiative wishes to encourage and engage all service providers and knowledge institutes active in the field of healthcare (including drug development, medical device development, ..., health economy, information management, privacy and security, legislation

From Metadata to request portal



<https://fair.healthdata.be/>
<http://dataforbetterhealth.be/>
<https://requests.healthdata.be/>

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Recent & future: sprint

Oct 2018

Workshop “Open & FAIR data”

When ? 18.10.2018

Where ? @DigiTyser

Audience ? Managers of
databases financed by
government



Recent & future: sprint

Oct 2017

Jan 2019

Workshop
“Open &
data”

Hackathon(s)

When ? #1: Intro: 10.01.2019 =>
hackathon: 25-26.01.2019

Where ? @DigiTyser

Audience ? Multidisciplinary data
science teams

Program ? ❶ During a workshop, an
governmental (administrative) database
will be presented by the responsible data
managers and primary users, metadata of
the database will be provided ❷ Attendees
of workshop can join the hackathon with
the governmental (administrative)
database.



Recent & future: sprint?

Oct 2017

Jan 2019

?Apr '19

Workshop
"Open & Engage"
da Hack

Presentation of Policy note

Minister M. De Block - Ontwerp van beleidsnota gezondheidsbeleid – 2018 - projet de note politique 'politique de santé'

When ? 2nd half of April

Where ? TBD

Audience ? All

Program ? ① presentation of
Policy note #dataforbetterhealth by
federal minister for Public Health,
dr. Maggie De Block

Minister M. De Block - Ontwerp van beleidsnota gezondheidsbeleid – 2018 - projet de note politique 'politique de santé'
versie – version 17/10/2017

1. Introduction générale

Afin de garantir la bonne qualité, la grande accessibilité et le coût abordable de nos soins de santé dans l'intérêt des patients et des prestataires de soins, il est nécessaire de les adapter aux évolutions de la société. C'est la raison pour laquelle j'ai mis en route d'importantes réformes dès le début de la législature et que d'importants efforts ont été fournis pour mettre en ordre et maintenir le

Heading to... Privacy-guarantee

4.5.2016

NL

Publicatieblad van de Europese Unie

L 119/1

VERORDENING (EU) 2016/679 VAN HET EUROPEES PARLEMENT EN DE RAAD

van 27 april 2016

betreffende de bescherming van natuurlijke personen in verband met de **verwerking** van persoonsgegevens en

Artikel 6

Rechtmatigheid van de verwerking

1. De **verwerking** is alleen rechtmatig indien en voor zover aan ten minste een van de onderstaande voorwaarden is voldaan:
 - a) de betrokkene heeft toestemming gegeven voor de **verwerking** van zijn persoonsgegevens voor een of meer specifieke doeleinden;
 - d) de **verwerking** is noodzakelijk om de vitale belangen van de betrokkene of van een andere natuurlijke persoon te beschermen;
 - e) de **verwerking** is noodzakelijk voor de vervulling van een taak van algemeen belang of van een taak in het kader van de uitoefening van het openbaar gezag dat aan de verwerkingsverantwoordelijke is opgedragen;

Het woordje “verwerking” is cruciaal !!
Wat is de interpretatie?

Heading to... Privacy-guarantee

Informed Consent (Hoeveel informed Consents kennen we?)

- eHealthPlatform Informed consent (afh. interpr. GDPR wel/niet verplicht):
 - Ikv “continuïteit van zorg”: uitwisselen ALLE medische gegevens (behalve persoonlijke notities)
- Klinische studie (verplicht):
 - informeren v/d patient: risico en gebruik gegevens (anoniem) om meer inzichten te verkrijgen tbv R&D (big data & AI)
- Bij opname/operatie (verplicht):
 - Informeren v/d patient: risico (en steeds vaker geïncludeerd: gegevens worden gebruikt ter verbetering persoonlijk traject en dragen bij om meer inzichten te verkrijgen tbv R&D (big data & AI)

Heading to ...

Strong Commitment database managers of federal administrations to fulfill their commitment AP18 (Keep up to date the metadata)...

Central request necessary: Only 29 requests are made (7 for Belgian cancer register)... (still in direct contact with...) Necessary for transparency, reusable,...

Make Available: link between databases

By Design: New administration solutions: Follow the OPEN DATA guidelines (see 2nd slide + European guideline 2018/0111)

AND

Heading to ... Inevitable: FAIR-principles

www.nature.com/scientificdata

SCIENTIFIC DATA

OPEN

SUBJECT CATEGORIES

» Research data

» Publication

characteristics

Received: 10 December 2015

Accepted: 12 February 2016

Published: 15 March 2016

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

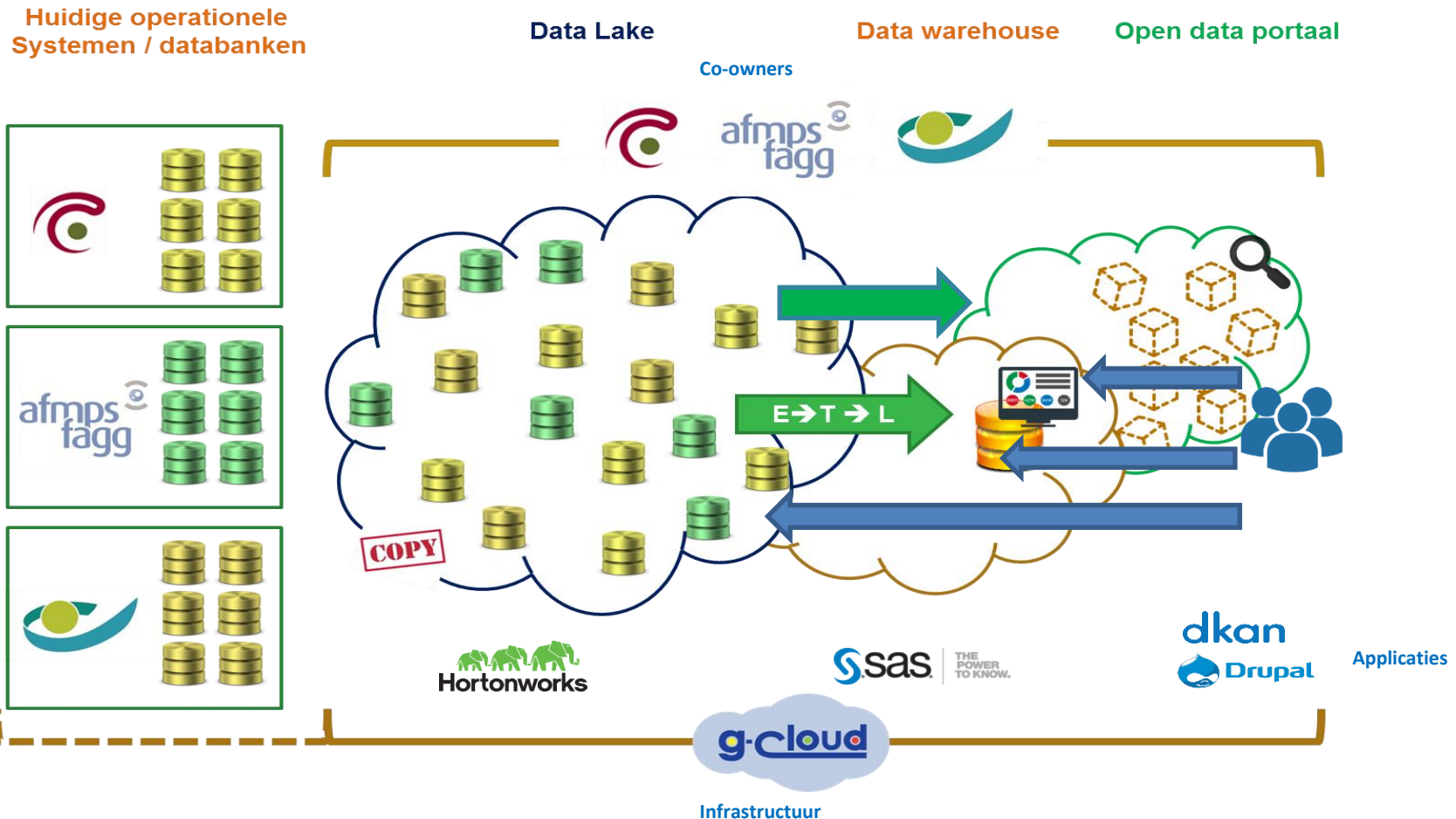
To be **Interoperable**:

- 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

Heading to... Acces to data(lake)



IMA

DATABANKEN, IMA ATLAS, PROCEDURES

LEIDDDRAAD VOOR VERGADERINGEN MET EXTERNE AANVRAGERS

IMA databanken: overzicht

Databank	Beschikbaarheid vanaf	Type data
Populatie	2002	Basis
Farmanet	2004	Basis
Gezondheidszorgen	2006	Basis
Katz	2008	Basis
Hoofdstuk IV	2014	Basis
Uitkeringen	2003 [2013 IFW]	Basis
EPS	2002	Afgeleid
Ziekenhuisopnames (klassiek/one day)	2006	Afgeleid
Contacten en patiëntenbestanden huisartspraktijken	2003	Afgeleid



#dataforbetterhealth is an **INITIATIVE** of the **federal minister of Public health**, the **federal minister of Digital Agenda**, the **federal Secretary of state Privacy**, **SUPPORTED** by Sciensano, NIDO - the innovation lab of the federal government and DigitYzer, and **INSPIRED** by RIZIV-INAMI, FOD-SPF Public Health, FAGG-AFMPS, IMA, IMEC, AGORIA, PHARMA.BE, VPP, LUSS, HOSPITALS.be, KCE, BOSA, ...

Questions

Q1: Are the databases of our industry-partners (pharma, medical devices, ...) also OPEN and FAIR?

Q2:....