sciensano

healthy all life long

SYMPOSIUM "HEALTH CHALLENGES OF THE 21ST CENTURY"

The collection and management of "real world data" for public health policy: past, present and future of the healthdata.be platform
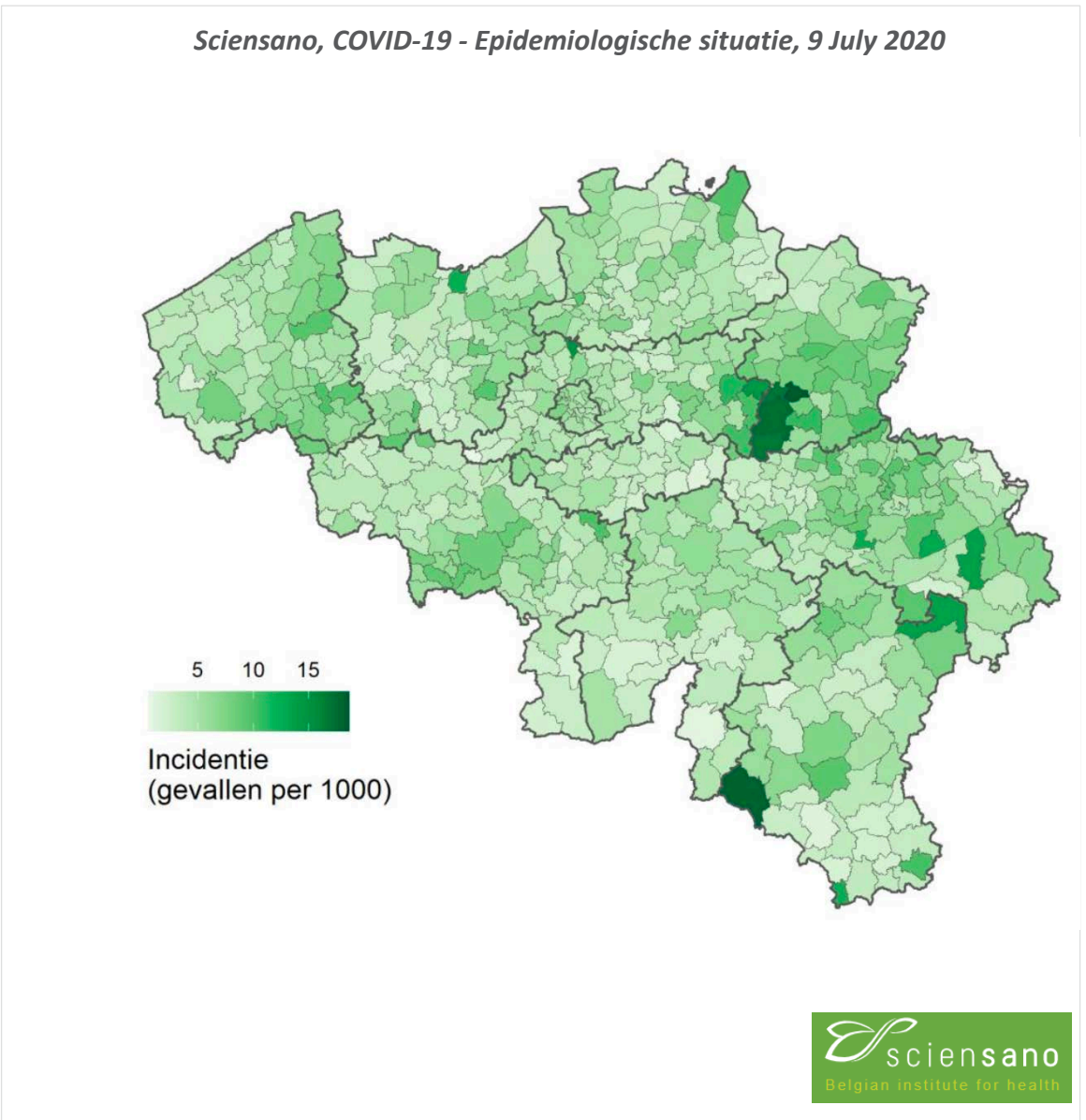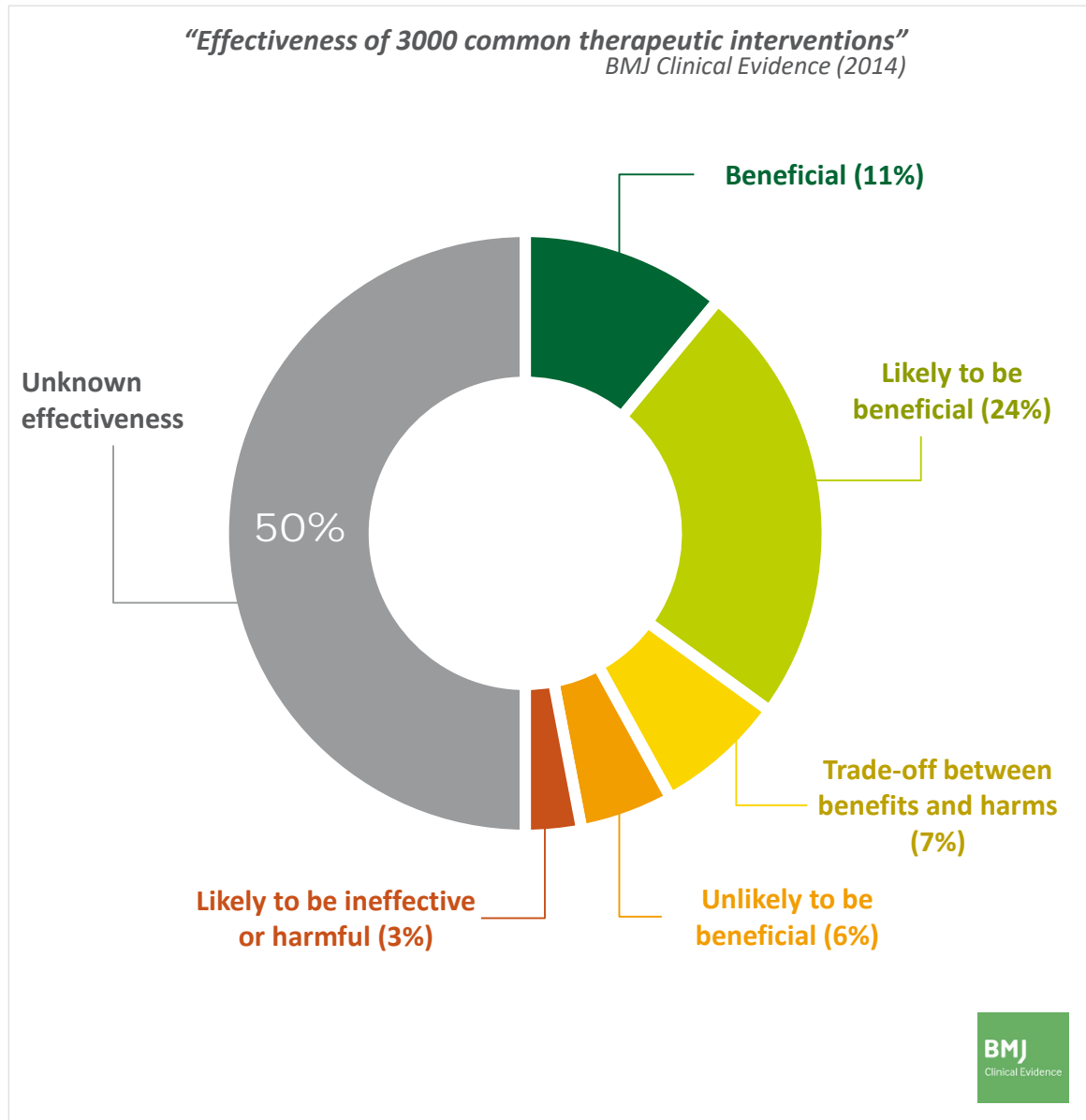
Sciensano Symposium 8 /12/2022 BEL Brussels

.be

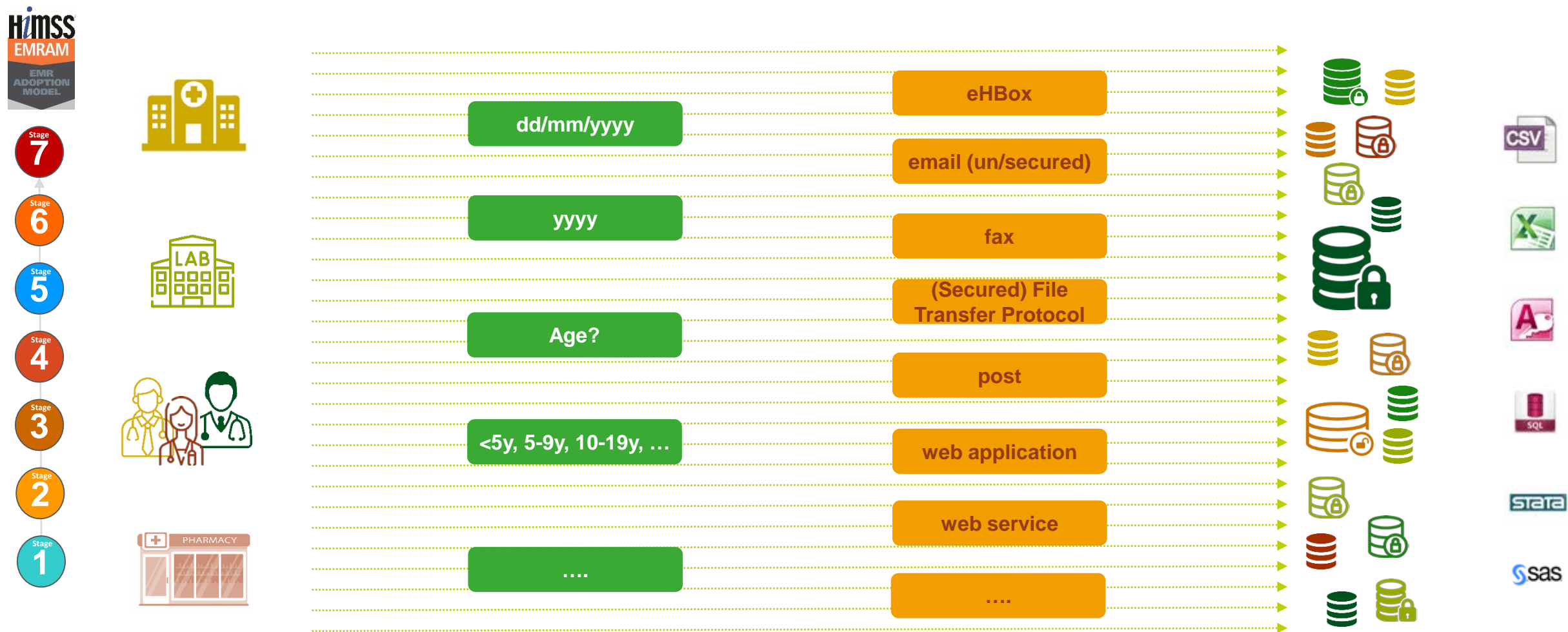# Real world data science in Belgian Public Health

… we have come a long way, a lot has been done, but a lot more still needs to be done …

2015   2023

Clinical & epidemiological registries and surveillances are necessary !

"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%)
- Unknown effectiveness 50%

Sciensano, COVID-19 - Epidemiologische situatie, 9 July 2020

5   10   15

Incidentie
(gevallen per 1000)
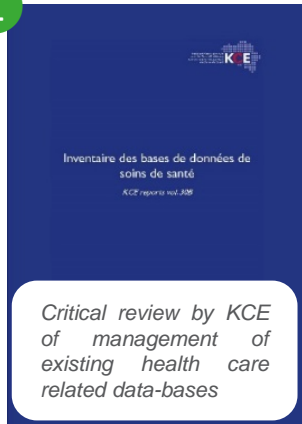
But high diversity in data collection and management practices exist

Roadmap towards a national health research infrastructure

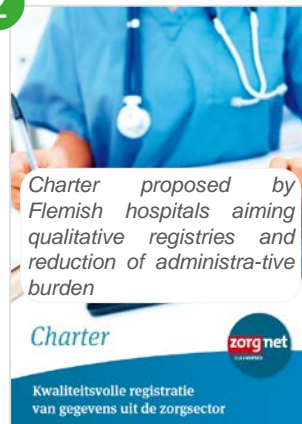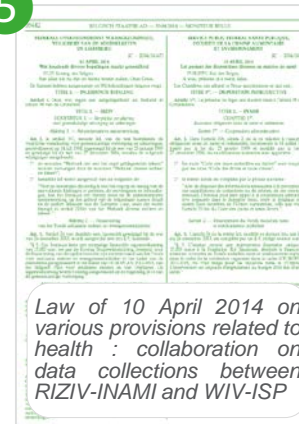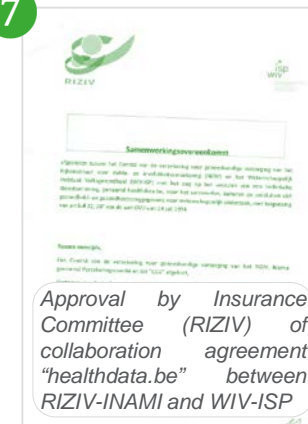**1** — *Critical review by KCE of management of existing health care related data-bases*

4 — *Feasibility study "health-data.be" by WIV-ISP, commissioned by RIZIV-INAMI*

6 — *Approval of technical architecture 1.0 of healthdata.be by eHealth Working Group Architecture*

8 — *Approval of technical architecture 1.0 of health-data.be by Sectoral Committee Health*

2006   2010   2013   2014   2015

2 — *Charter proposed by Flemish hospitals aiming qualitative registries and reduction of administra-tive burden*

3 — *2nd Action plan eHealth 2013-2018: Action point 18: patient registries*

5 — *Law of 10 April 2014 on various provisions related to health : collaboration on data collections between RIZIV-INAMI and WIV-ISP*

7 — *Approval by Insurance Committee (RIZIV) of collaboration agreement "healthdata.be" between RIZIV-INAMI and WIV-ISP*

2015: healthdata.be - service provider in collection & management of health related data

Real world data science in Belgian Public Health
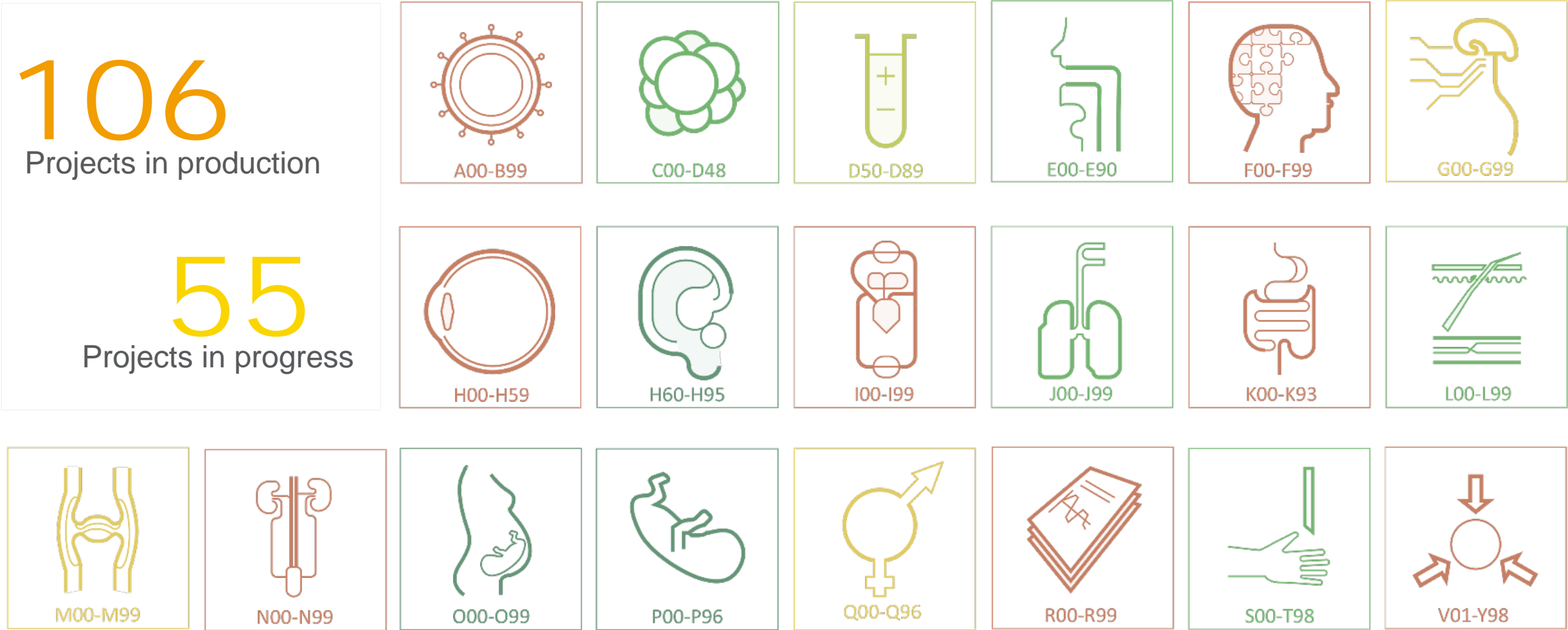
… we have come a long way, **a lot has been done**, but a lot more still needs to be done …

2015

2022: projects supported by healthdata.be cover full bio-medical spectrum

106 Projects in production

55 Projects in progress

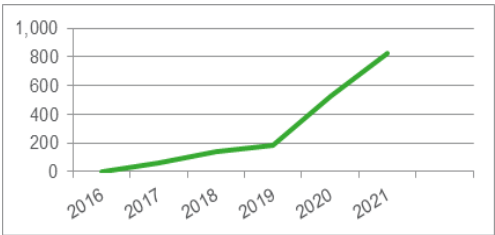|					
A00-B99	C00-D48	D50-D89	E00-E90	F00-F99	G00-G99
H00-H59	H60-H95	I00-I99	J00-J99	K00-K93	L00-L99
M00-M99	N00-N99	O00-O99	P00-P96	Q00-Q96	R00-R99	S00-T98	V01-Y98

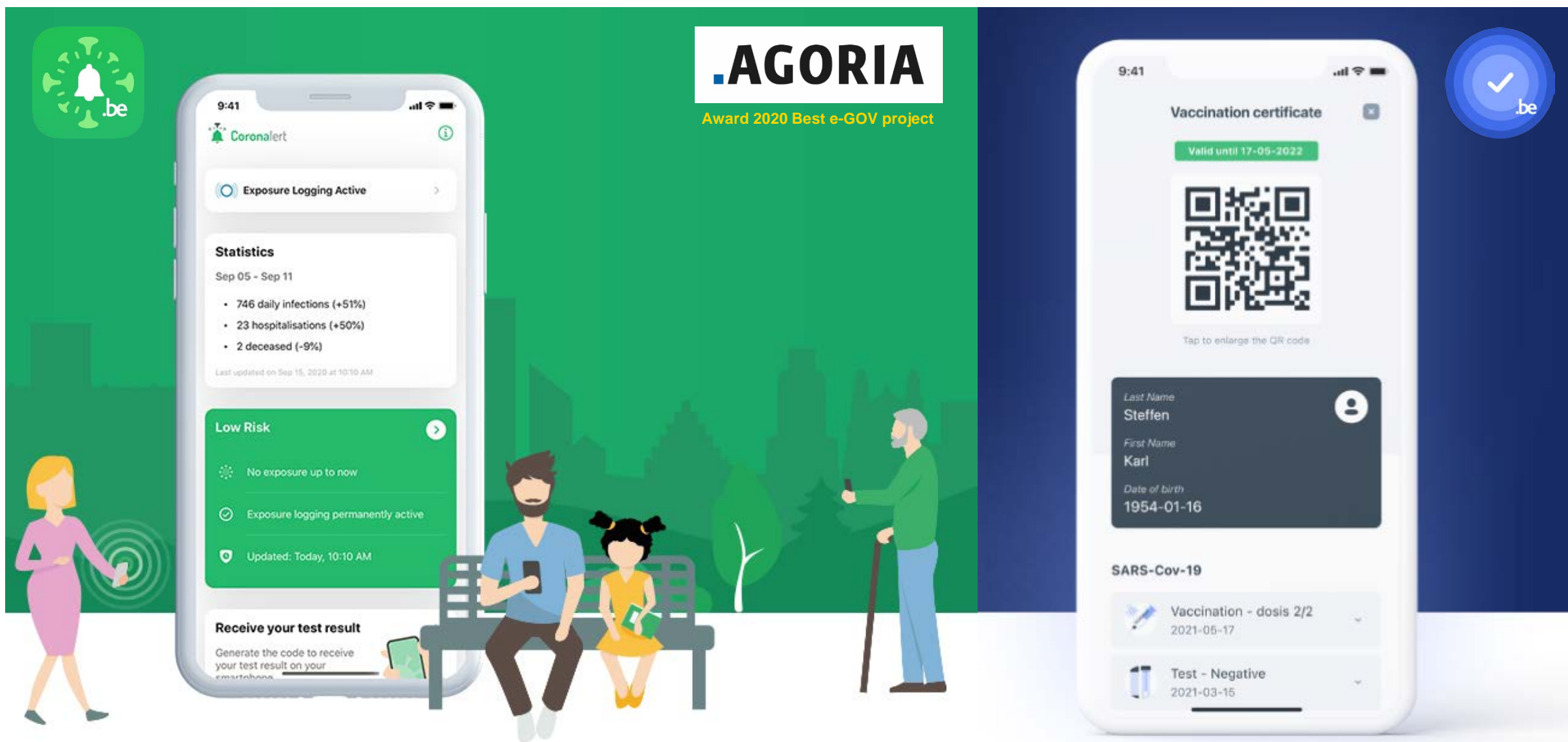# 2022: very diverse users group of healthdata.be services

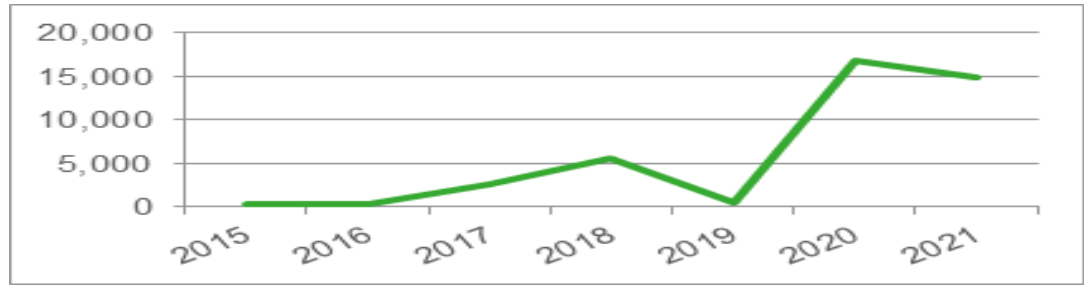**824**

User accounts on datawarehouse

2020: SARS-CoV-2 as challenge for data collection & management system

| 1 | Person **NEEDS TO BE TESTED** | 2 | Patient gets **PRESCRIPTION** or CTPC | 3 | Patient goes to **PLACE TO TEST** and **SAMPLE** is taken | 4 | Transport of **SAMPLE** | 5 | **SAMPLE ANALYSIS** | 6 | Laboratory **TEST RESULT** available | 7 | **PATIENT RECEIVES RESULTS** | 8 | Results are received on **DATABASES** | 9 | 1A ticket creation | 10 | Patient successfully reached |

With contributions to new services impacting daily life

Coronalert

9:41

Coronalert

Exposure Logging Active

Statistics

Sep 05 - Sep 11

- 746 daily infections (+51%)
- 23 hospitalisations (+50%)
- 2 deceased (-9%)

Last updated on Sep 15, 2020 at 10:10 AM

Low Risk

No exposure up to now

Exposure logging permanently active

Updated: Today, 10:10 AM

Receive your test result

Generate the code to receive your test result on your smartphone.

.AGORIA

Award 2020 Best e-GOV project

9:41

Vaccination certificate

Valid until 17-05-2022

Tap to enlarge the QR code

Last Name
Steffen

First Name
Karl

Date of birth
1954-01-16

SARS-Cov-19

Vaccination - dosis 2/2
2021-05-17

Test - Negative
2021-03-15

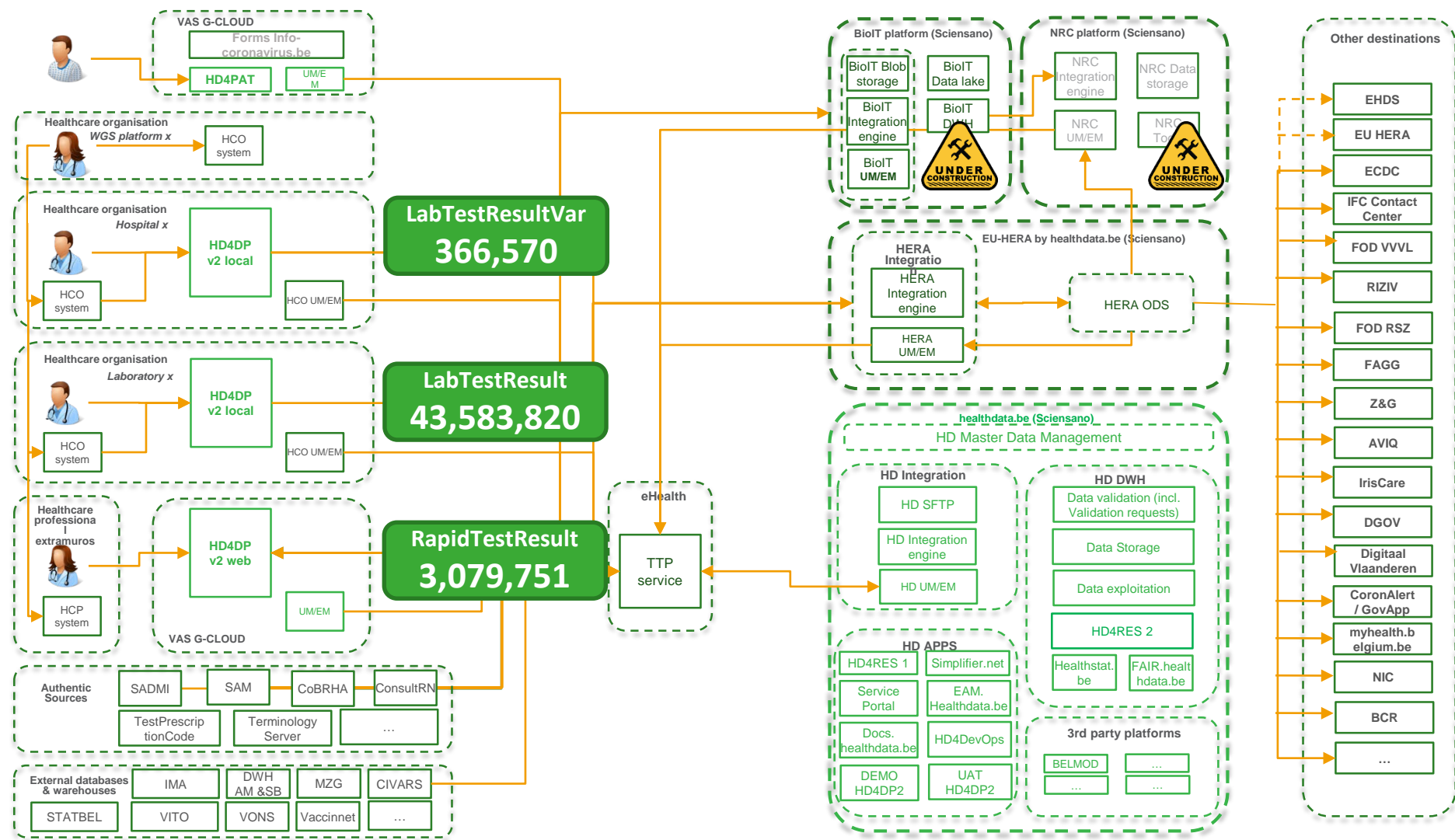# Many and diverse data providing organisations and individuals
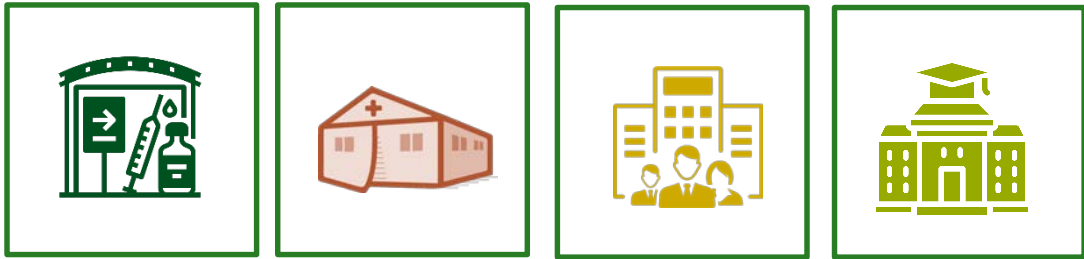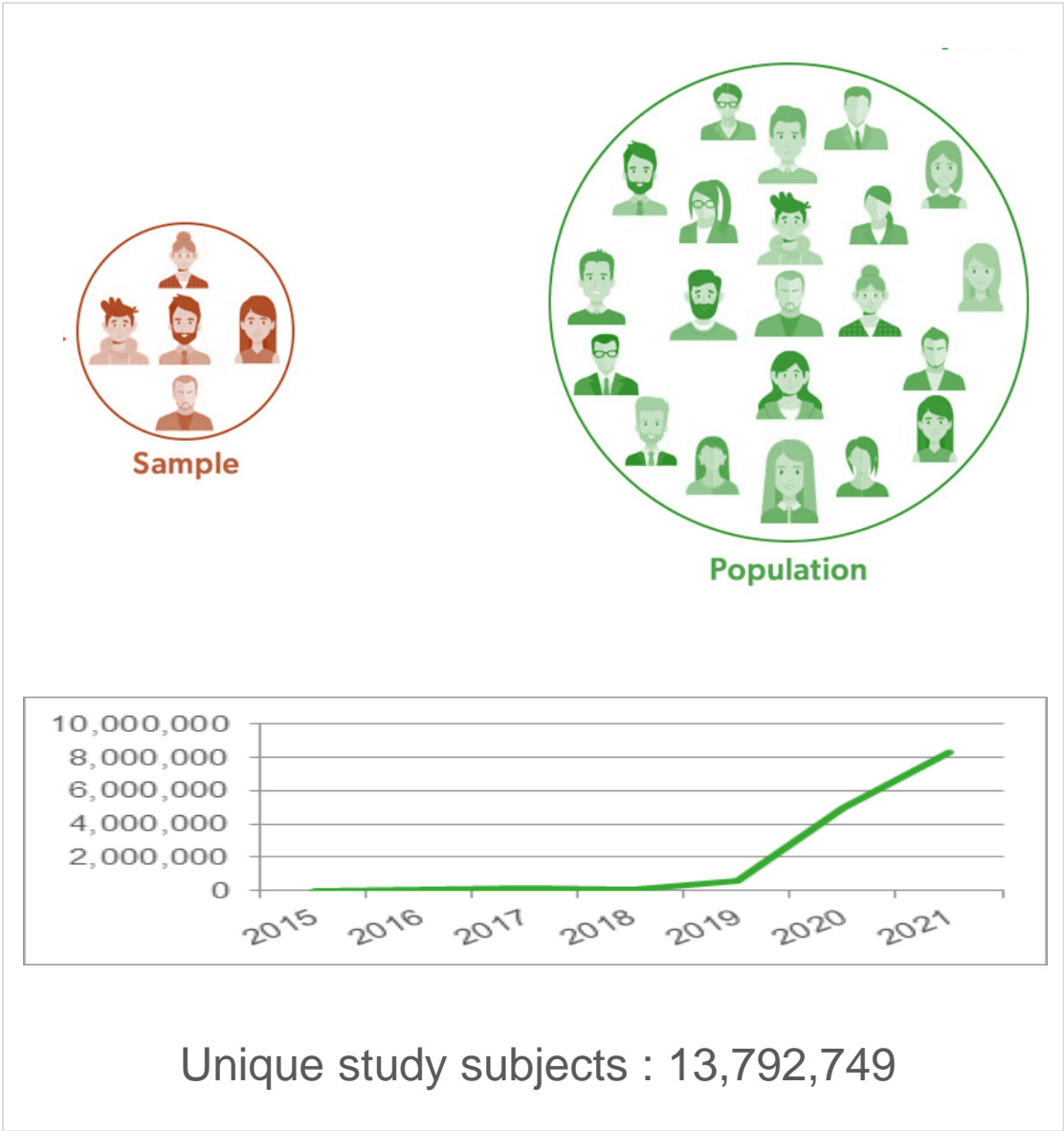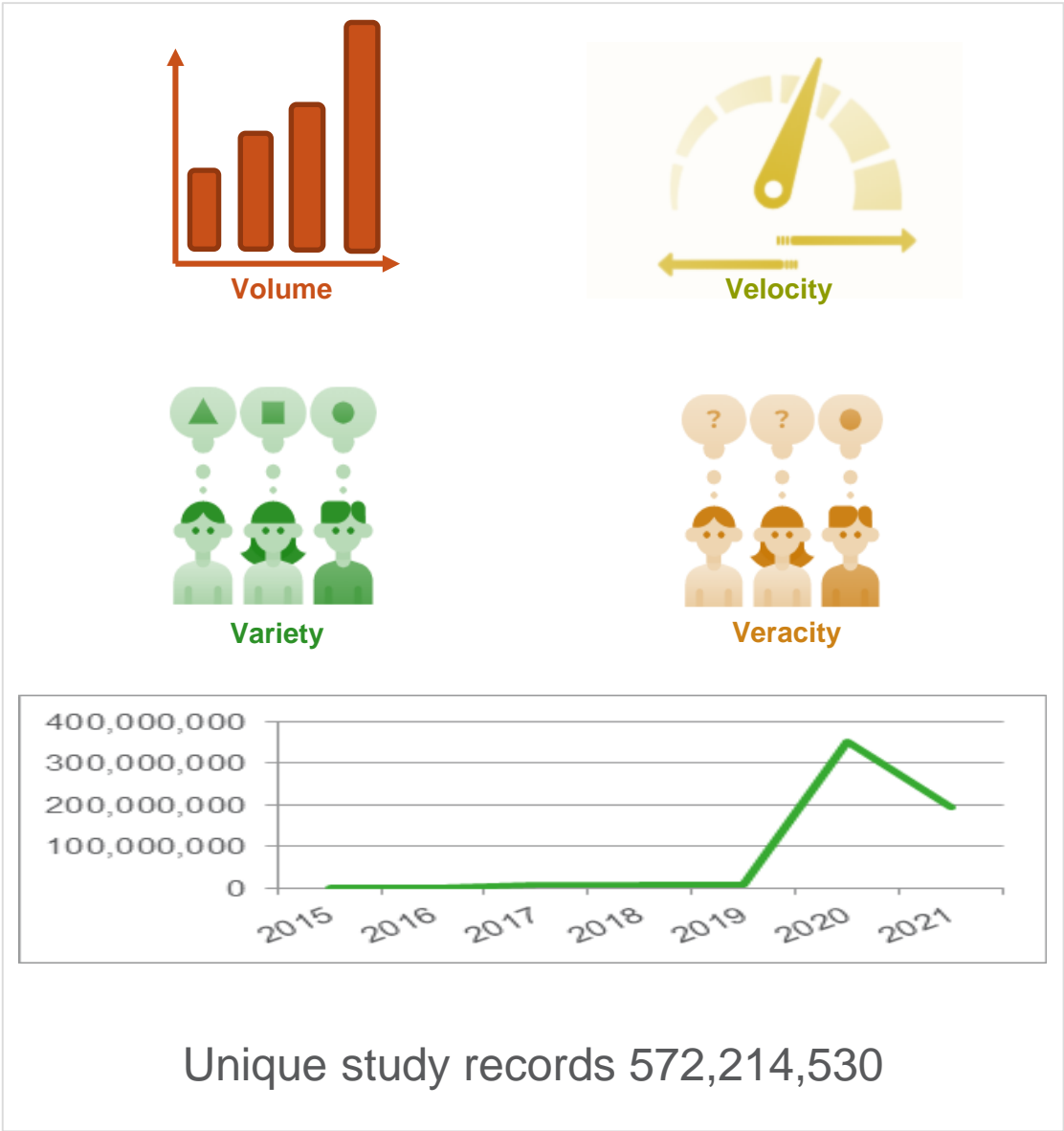

Organisations providing data: 16,856
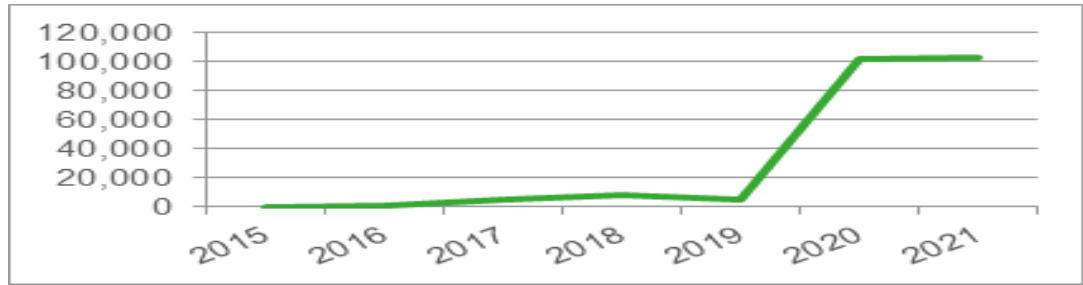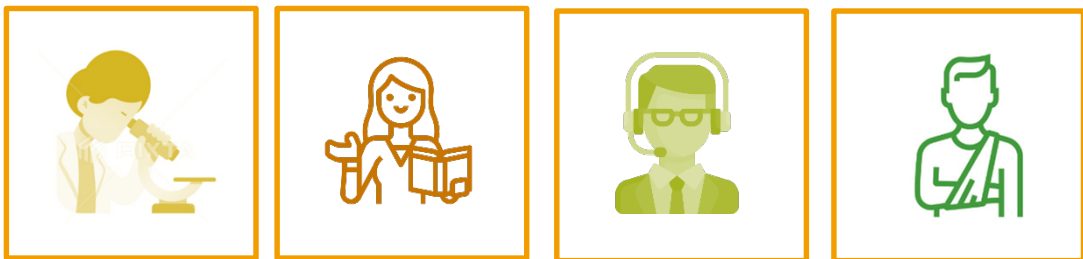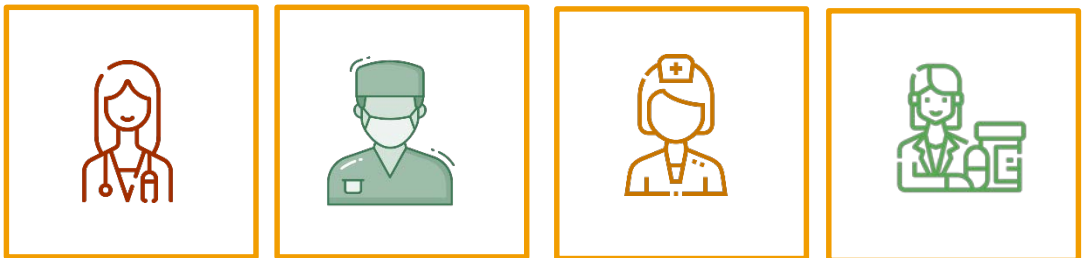
Professionals providing data: 103,117

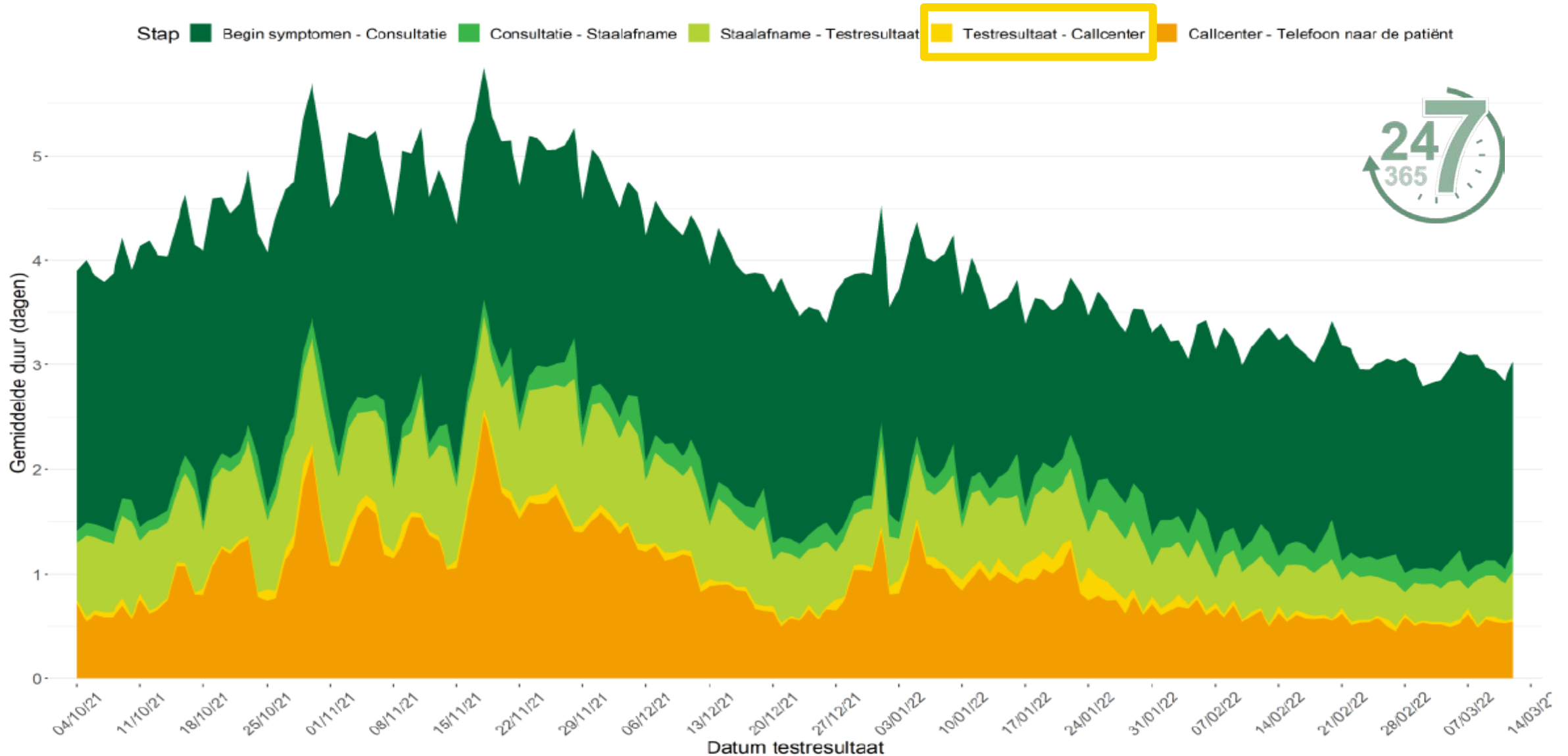# A continuous technical integration in Belgian ehealth landscape

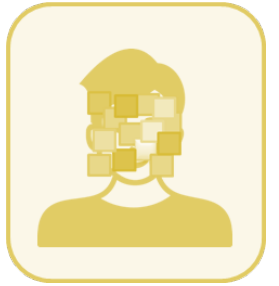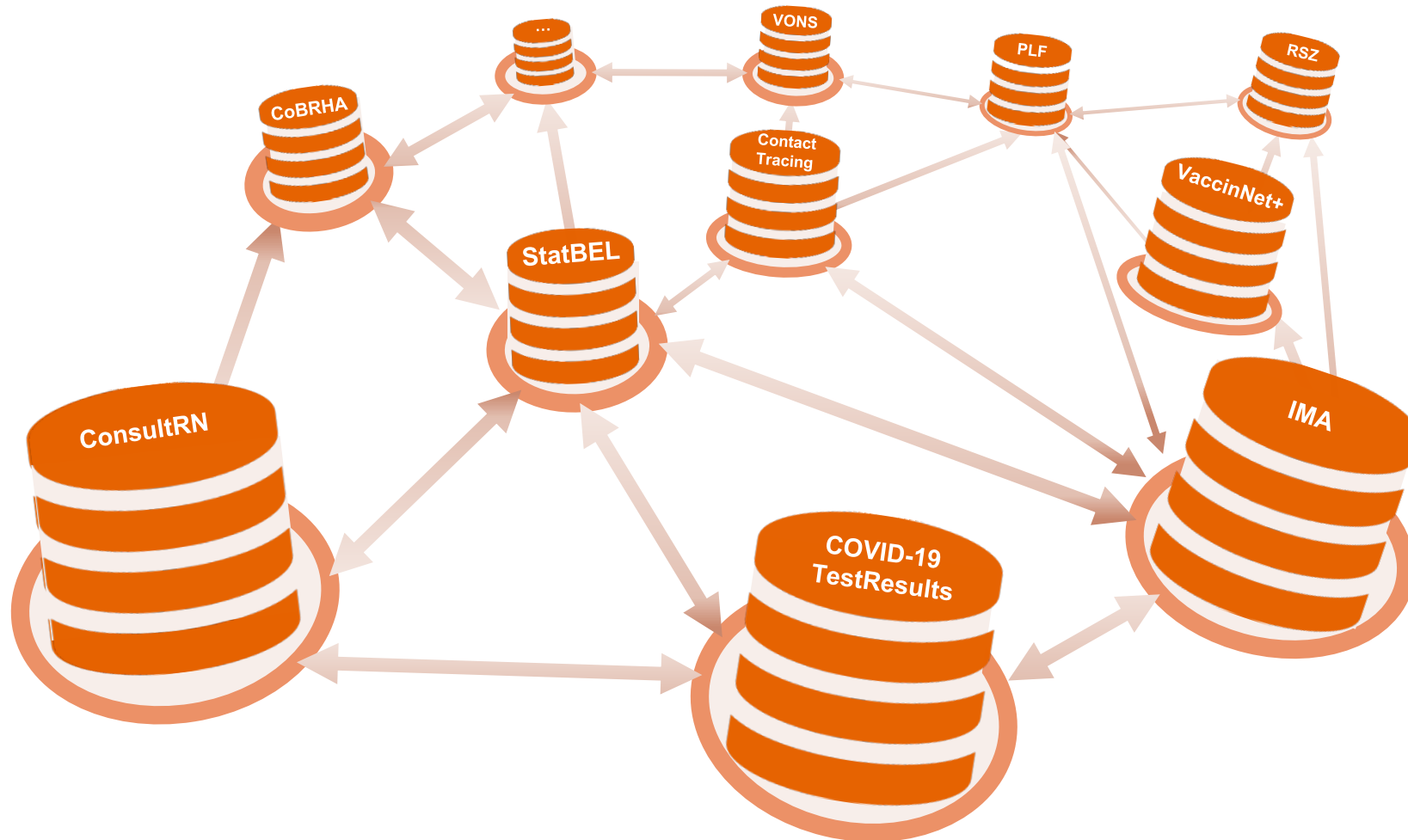# With a continuous stream of high volumes, diverse and changing data

Unique study records 572,214,530

Unique study subjects : 13,792,749

Performance indicator (proxy) laboratories and healthdata.be

Proesmans K, Hancart S, Braeye T, Klamer S, Robesyn E, Djiena A, De Leeuw F, Mahieu R, Dreuw A, Hammami N, Wildemeersch D, Cornelissen L, Van Cauteren D. COVID-19 contact tracing in Belgium: main indicators and performance, January - September 2021. Arch Public Health. 2022 Apr 13;80(1):118. doi: 10.1186/s13690-022-00875-6. PMID: 35418097; PMCID: PMC9005619.

SARS-CoV-2 accelerated "linked data".
But optimisation and maintenance is needed "to be prepared"

Scientific output by users based on data at healthdata.be
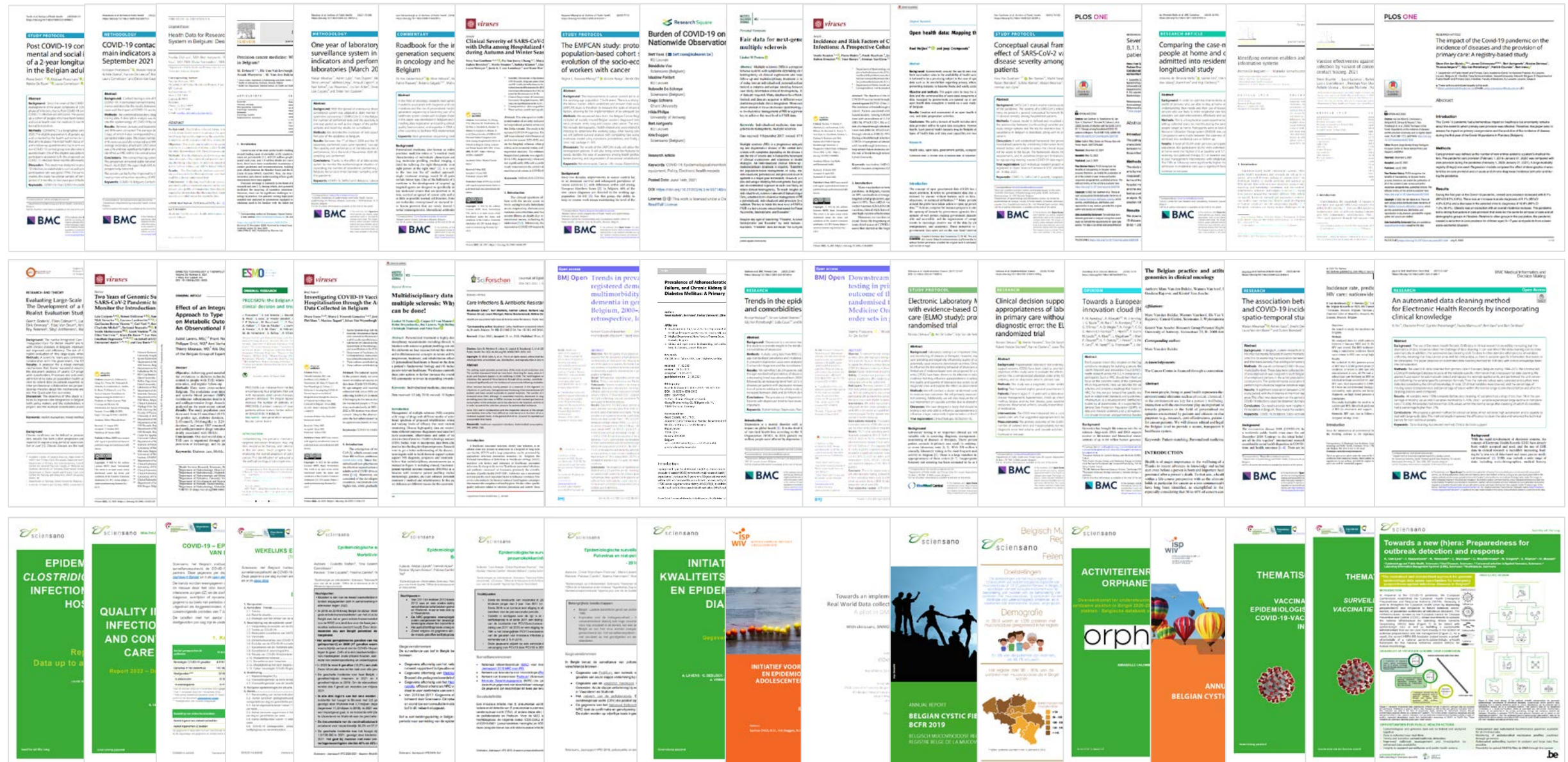
Preparedness : shift from descriptive towards "prescriptive" analytics

value

complexity

preparedness

information

foresight

insight

hindsight

Descriptive analytics
"What happened?"

Diagnostic analytics
"Why did it happen?"

Predictive analytics
"What will happen?"

Prescriptive analytics
"What to do when it happens?"
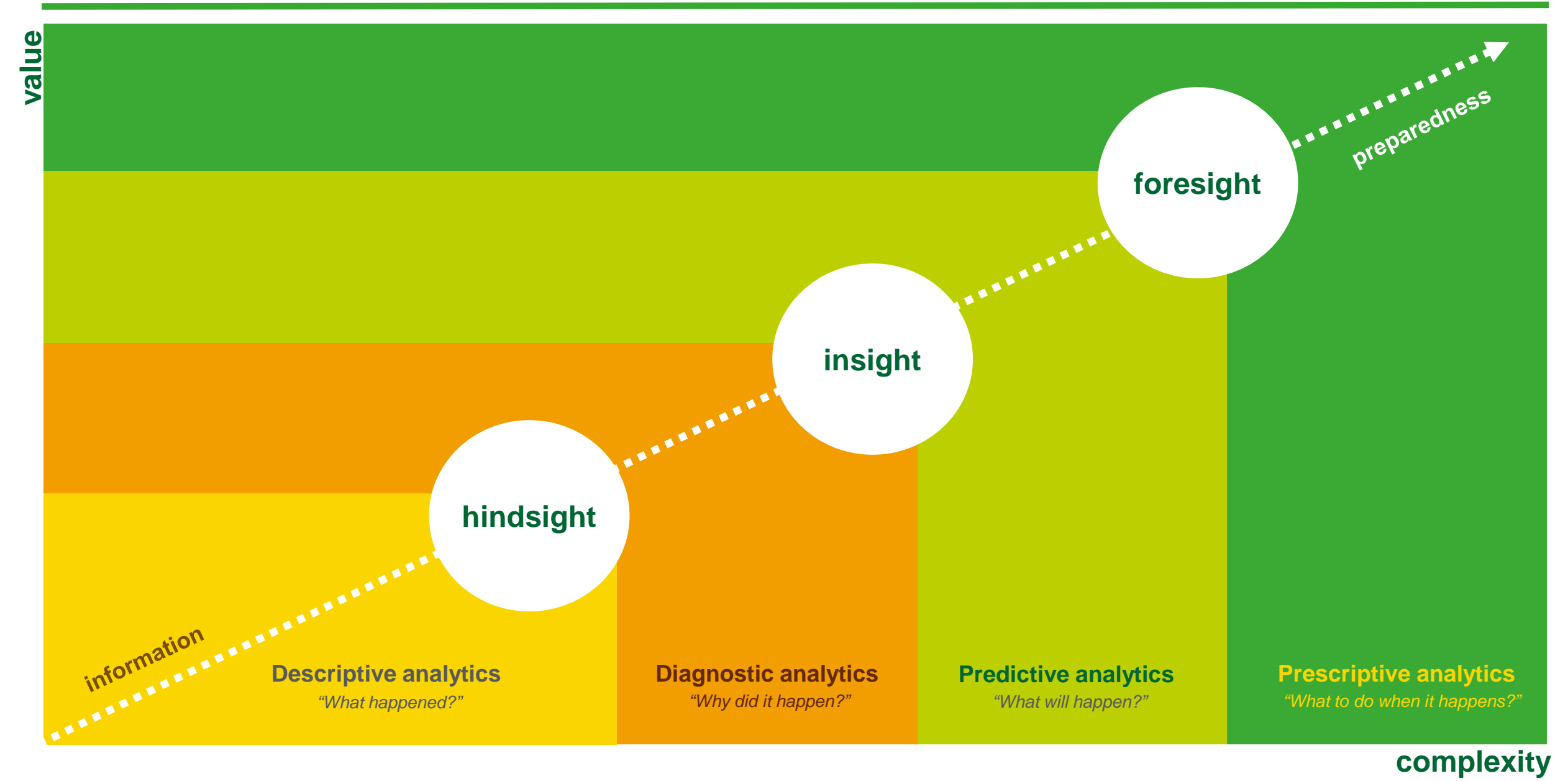
"IT's still not an easy journey"
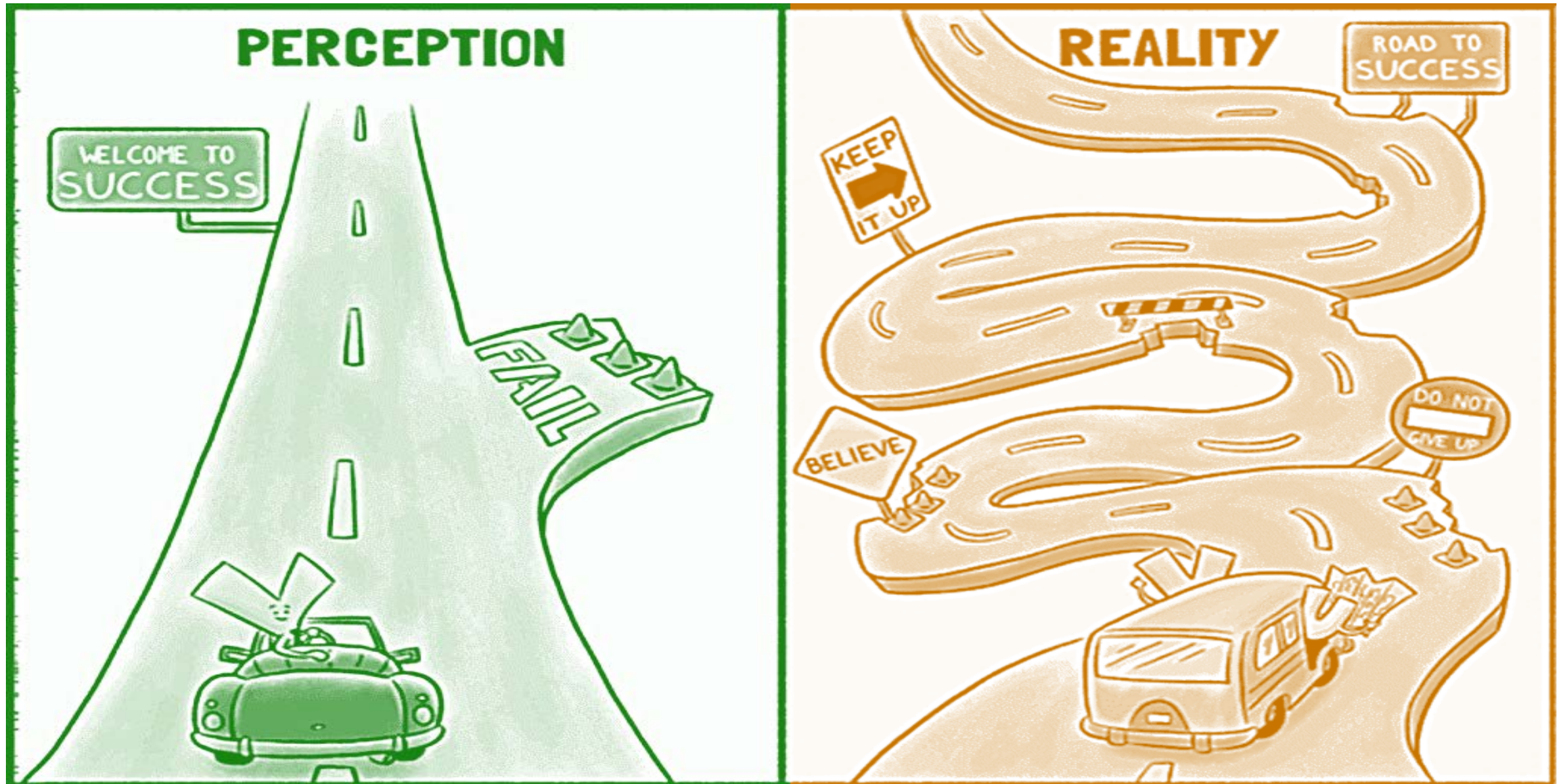
Real world data science in Belgian Public Health

we have come a long way, a lot has been done, **but a lot more still needs to be done**

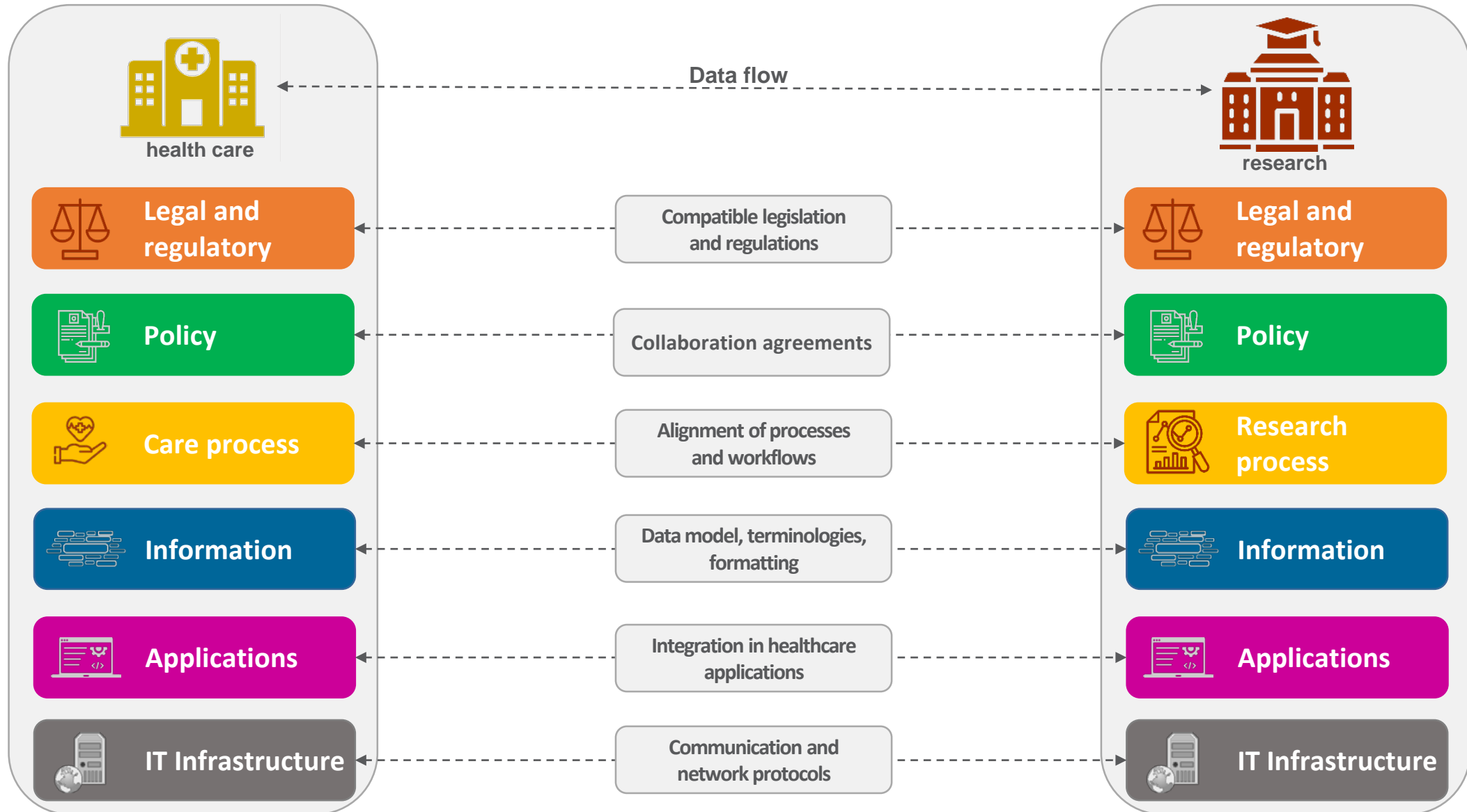2015

2023

"Interoperability" as key success factor for real-world data science
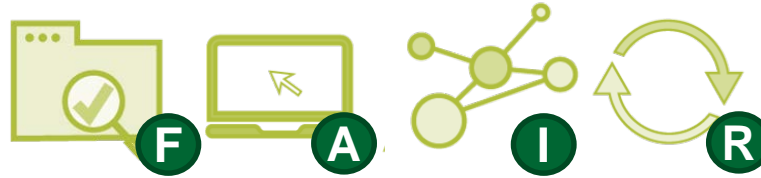
Road (opportunities & challenges) ahead ...

1 Prioritization of actions to bring current platform to *"Plateau of productivity"* (© Gartner)

2 Shift from IT-centric approach towards *User-centric* services

3 Optimization of research objects in terms of *Findable*, *Accessible*, *Interoperable* and *Reusable* both for machines and for people

4 Implement *SNOMED-CT* as main structured clinical vocabulary

5 Implement *HL7 FHIR* as standard for data formats and elements and as application programming interface for exchanging electronic health records

2023…

6 Facilitate the collection and processing of *genomics data*.

7 Align and connect with methods and applications from *EU Health Emergency Preparedness and Response Authority (HERA)*.
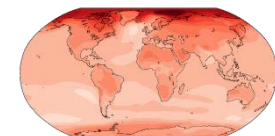
8 Adopt methods and applications from *Observational Health Data Sciences and Informatics* to increase re-use of data.

9 Make *synthetic data* and analytical pipeline available to increase re-use and decrease lead times.

10 Facilitate other emerging health research topics by harvesting data from other *societal* and *environmental sources*.

www.healthdata.be

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