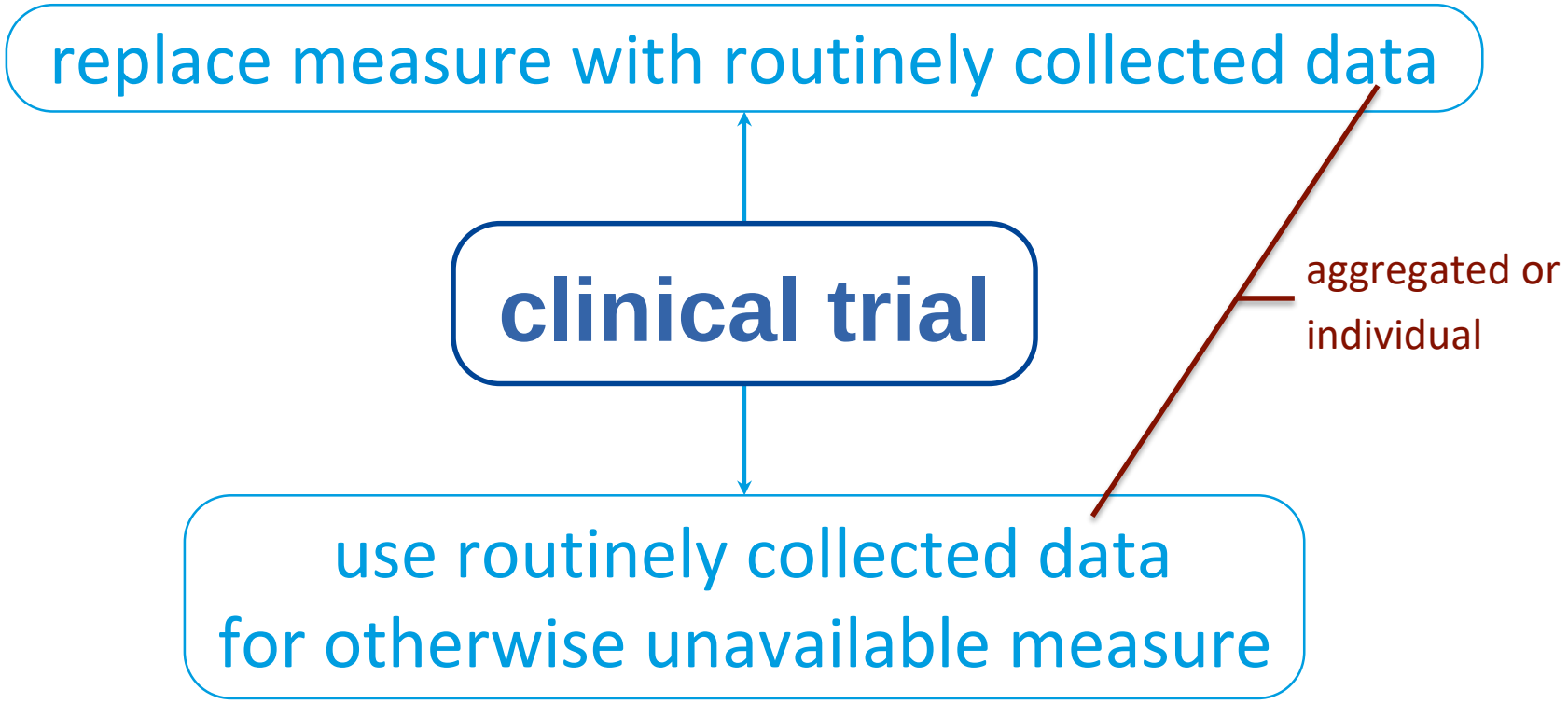
Registries of health care data in Belgium: a bird's eye view

Stephan Devriese

point of view



assumptions

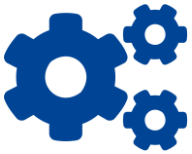


access



privacy

- proportionality
- finality

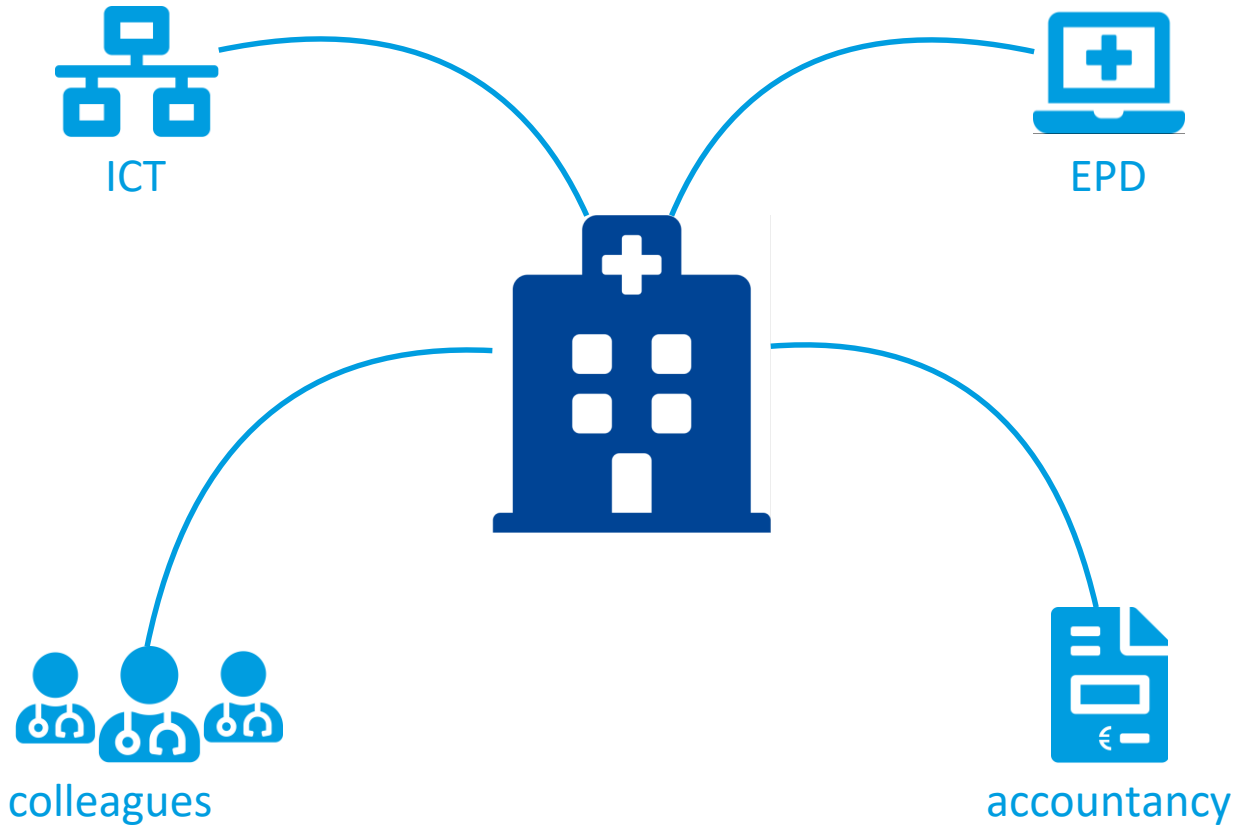


technology

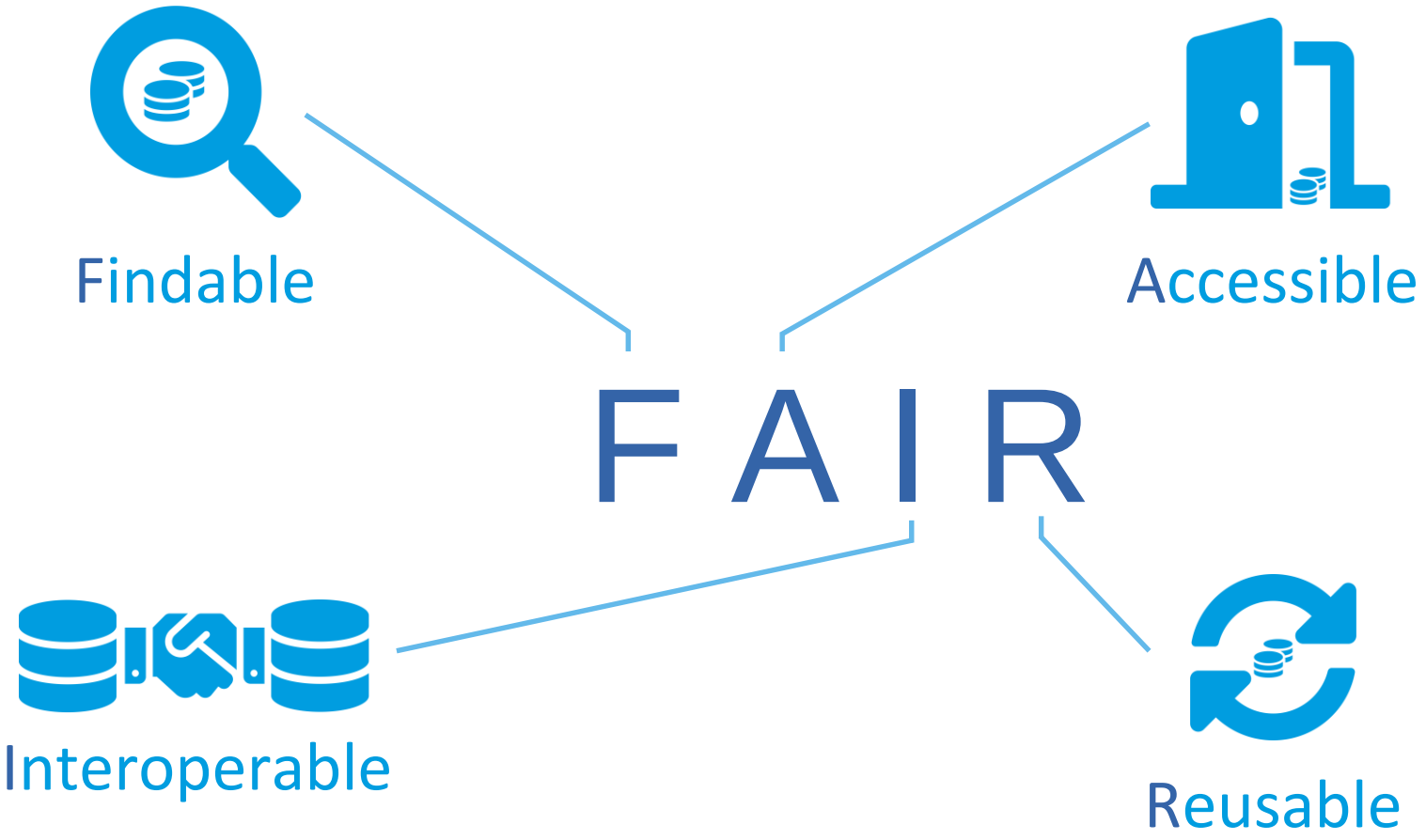
where to find registries?



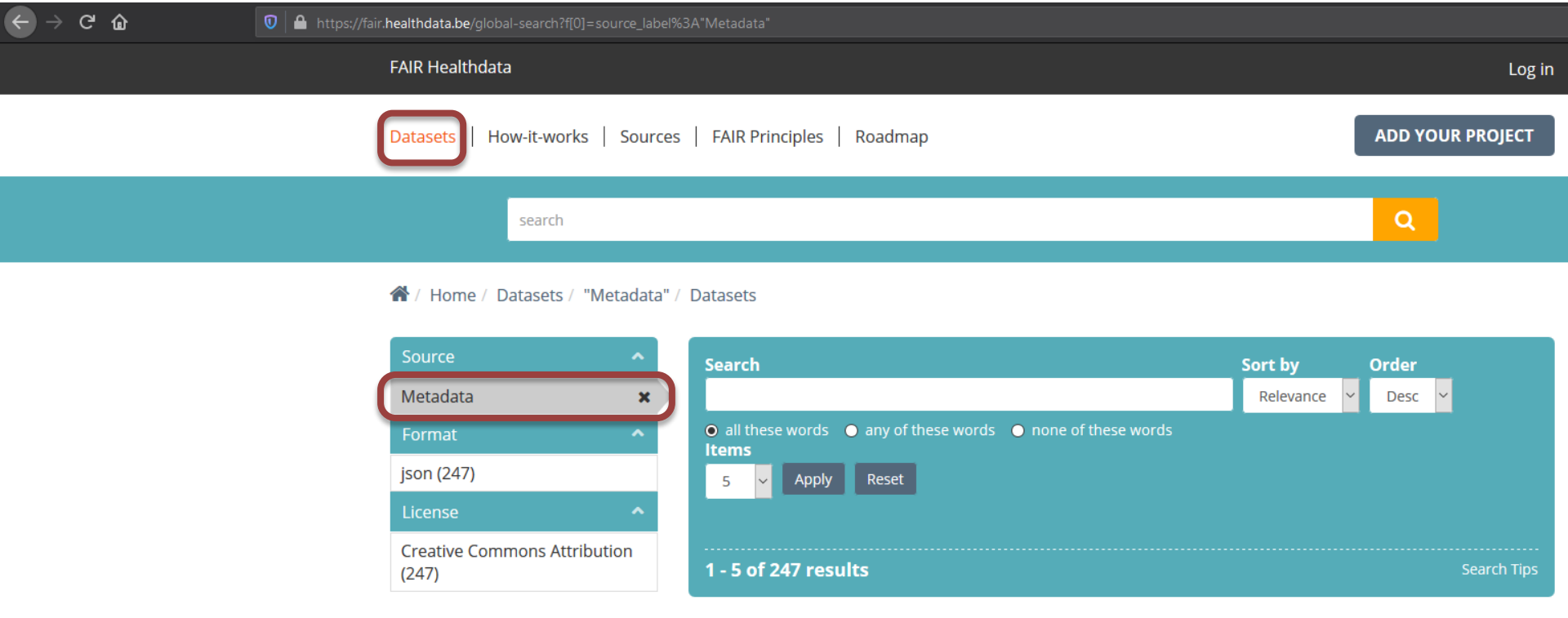
the unusual suspects



fair.healthdata.be



fair.healthdata.be



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- Protocol
- Sponsor(s)
- Commissioner(s)
- Source(s) of Monetary or Material Support
- Governance
- General information
- Legal basis
- Design of the project
- Sites involved in the project
- Health professionals involved (encoding) in the project
- Informed consent
- Review
- Data dictionary
- Data quality
- Data storage
- Data access

Request data

federated entities

Vlaanderen ZORG-EN-GEZONDHEID.BE

AGENTSCHAP ZORG & GEZONDHEID

www.zorg-en-gezondheid.be

Home › Actiedomeinen › Observatorium voor Gezondheid en Welzijn van Brussel-Hoofdstad

Observatorium voor Gezondheid en Welzijn van Brussel-Hoofdstad

www.ccc-ggc.brussels/nl/observatbru/accueil



sante.wallonie.be

Wallonie familles santé handicap AVIQ

Portail SANTE

Accueil » La Santé »

www.dg.be

DG.be

DG en Belgique | Région de vie | Région frontalière | Région économique | Région de

a selection of organisations

RIZIV

federale overheidsdienst
VOLKSGEZONDHEID,
VEILIGHEID VAN DE VOEDSELKETEN
EN LEEFMILIEU

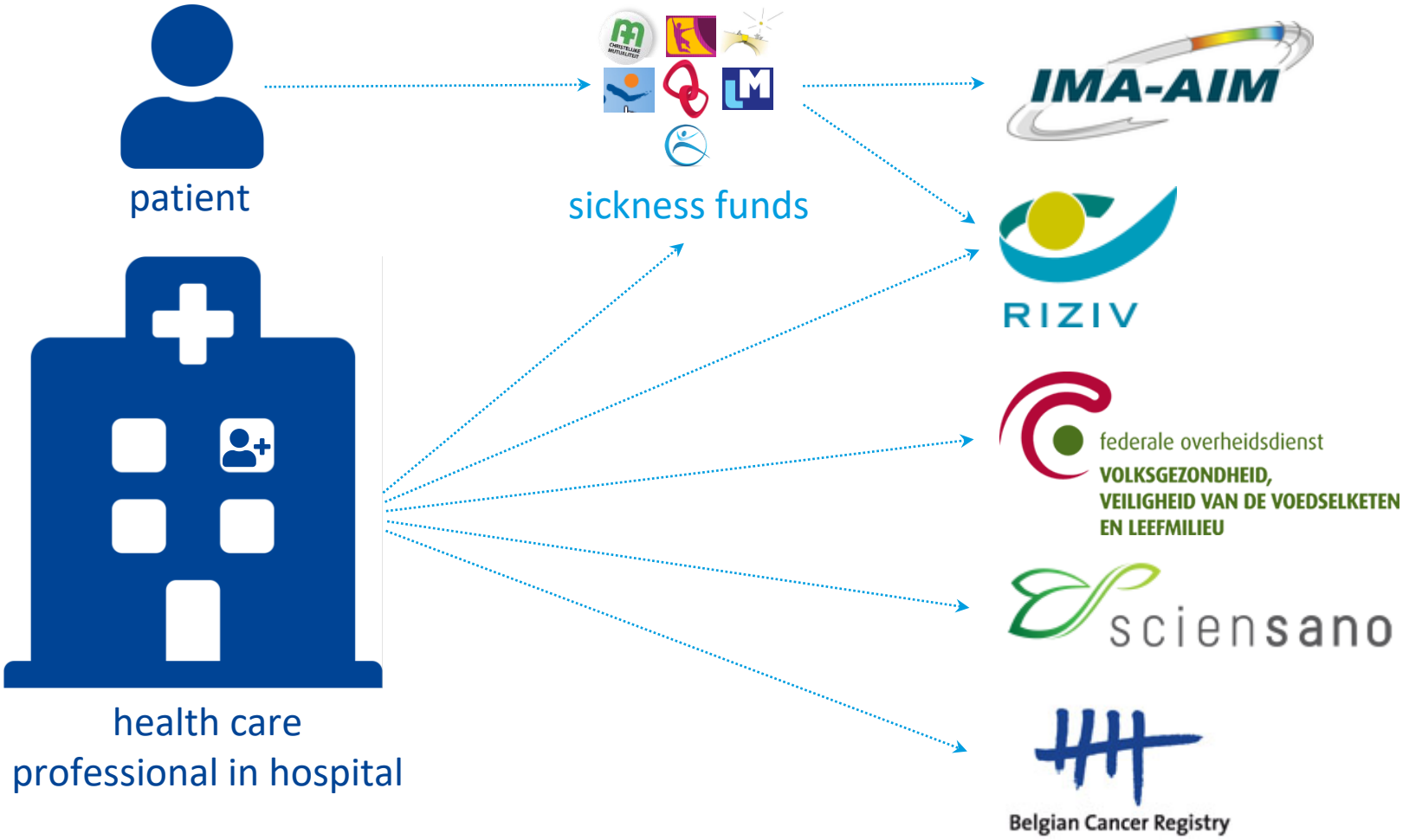


Belgian Cancer Registry

sciensano

IMA-AIM

data flow


patient
sickness funds
IMA-AIM
RIZIV
federale overheidsdienst
VOLKSGEZONDHEID,
VEILIGHEID VAN DE VOEDSELKETEN
EN LEEFMILIEU
sciensano
Belgian Cancer Registry
health care
professional in hospital

sciensano

epidemiology & public health

- HSR
- Cancer centre
- Public health and genome
- Lifestyle and chronic diseases
- Epidemiology of infectious diseases
- Healthcare-associated infections
- Veterinary epidemiology
- Crisis
- EU health information system

infectious diseases in humans

- Foordborne pathogens
- Bacterial diseases
- Viral diseases
- Mycology and aerobiology
- Immune response
- Laboratory and medical microbiology

infectious diseases in animals

- Coordination of veterinary activities
- …

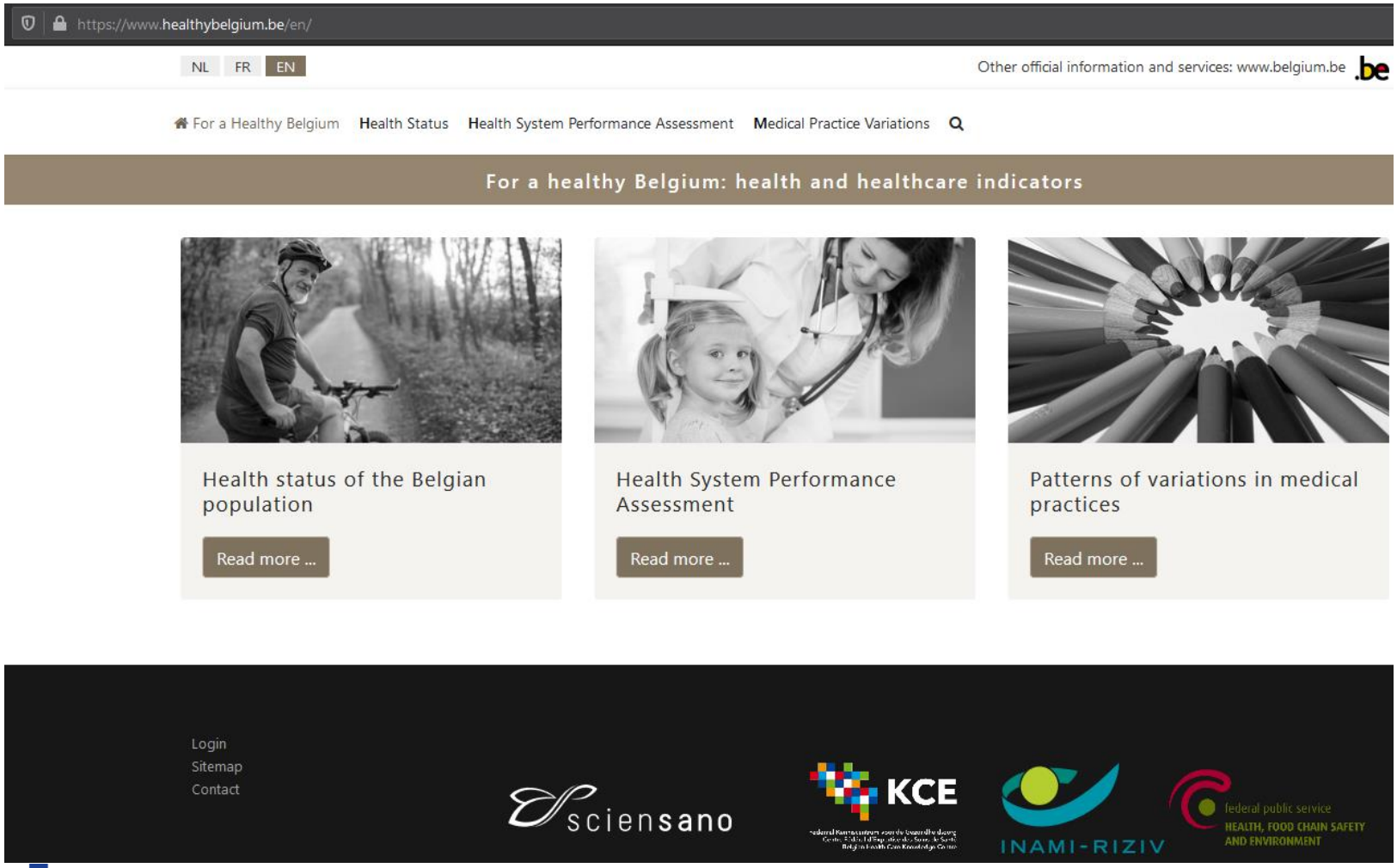
chemical & physical health risks

- Medicines and health products
- Organic contaminants and additives
- Trace elements and nanomaterials
- Risk and health impact assessment
- Platform chromatography and mass spectometry

other

- Quality, safety, genomics, healthdata.be, …

For a healthy Belgium



federale overheidsdienst
VOLKSGEZONDHEID,
VEILIGHEID VAN DE VOEDSELKETEN
EN LEEFMILIEU

FPS Public Health

quality & organization

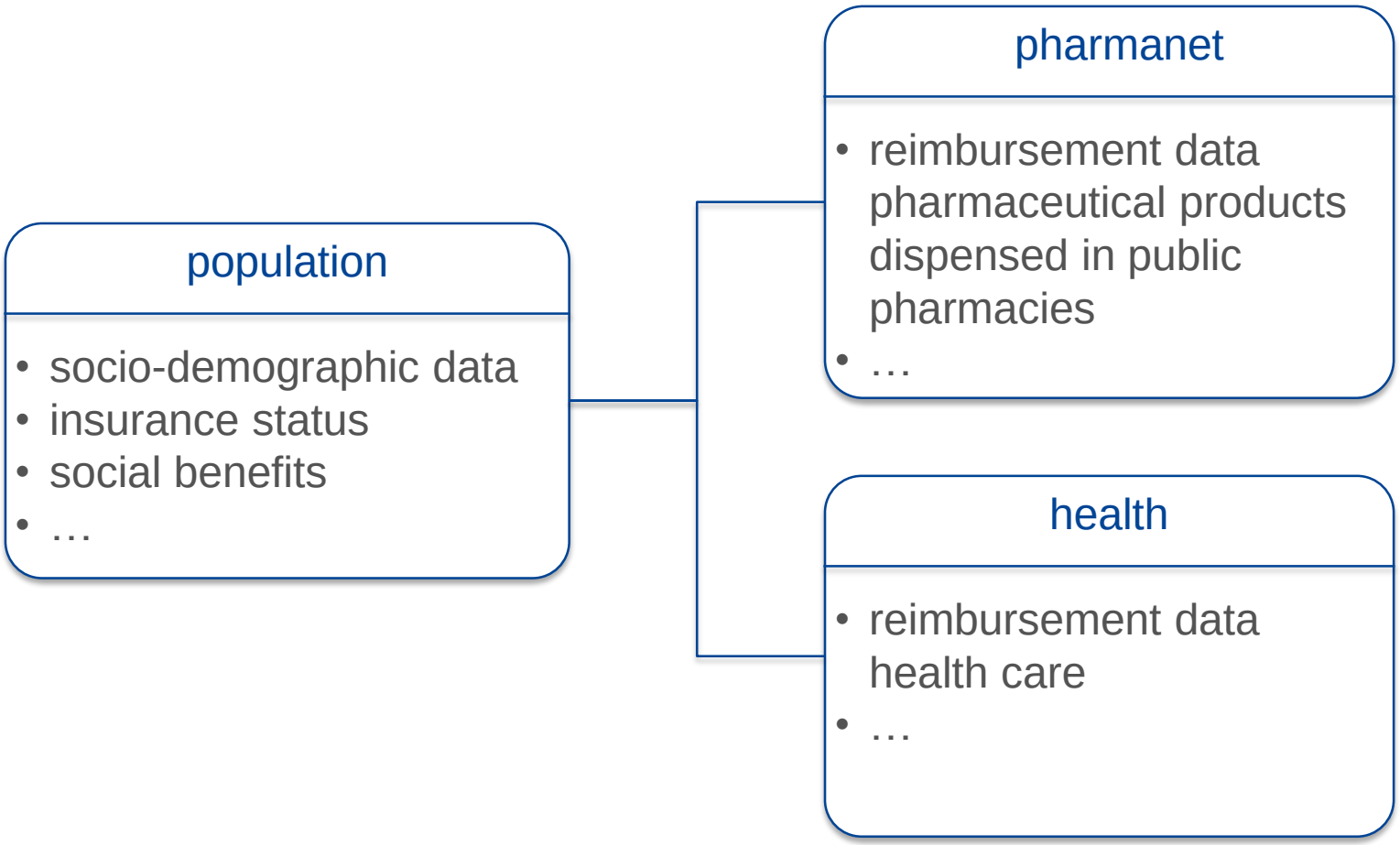
- StatHosp
- Colleges
- BAPCOC
- Pain
- Clinical pharmacy
- CFQAI
- SDD – IHAB
- P4P
- Patient security
- …

data managamenent

- MZG – RHM
- MPG – RPM
- MUG – SMUR – PIT
- Medical imagery
- CIC
- Hospital characteristics
- …

hospital financing

- FINHOSTA
- BFM – BMF
- …


pharmanet
• reimbursement data pharmaceutical products dispensed in public pharmacies
• …
population
• socio-demographic data
• insurance status
• social benefits
• …
health
• reimbursement data health care
• …

Stichting Kankerregister
Fondation Registre du Cancer

Belgian Cancer Registry

BCR

- socio-demographic data
- diagnostic data
- topography
- laterality
- morphology
- tumor type
- TNM
- WHO scoring
- survival data
- protocol
- …

from IMA–AIM

- subset of reimbursement data
- subset of population data

RIZIV–INAMI

authentic sources

- nomenclature
- reimbursed pharmaceutical products
- implants
- regulations
- ...

registers

- nursing homes
- health care providers
- availability fees
- permanence fees
- sponsor of multiple registers hosted elsewhere
- ...

access

IVC–CSI

Informatieveiligheidscomité

Comité de sécurité de l'information

chamber
Federal Government

residuary competence

chamber Social Security
and Health

authorising competence

access

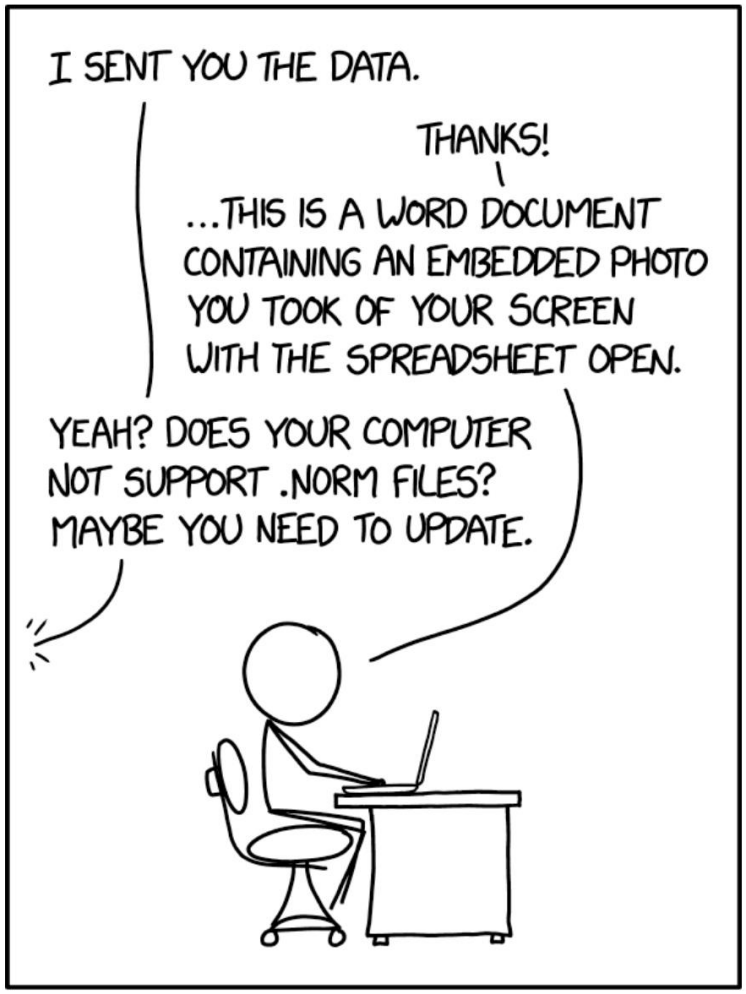
- Trusted Third Party services
- Connector projects to various registers
- Referral repertory
- …

- Sciensano registers
- Other registers
- Standardisation efforts
- Health care actor access
- …

quality of registration

- register dependent
  - data driven
  - on site audit
- fair.healthdata.be
  - data quality section + reports:
    - validity
    - reliability
    - timeliness
    - precision
    - integrity
- use in other research

xkcd.com


I SENT YOU THE DATA.
THANKS!
...THIS IS A WORD DOCUMENT CONTAINING AN EMBEDDED PHOTO YOU TOOK OF YOUR SCREEN WITH THE SPREADSHEET OPEN.
YEAH? DOES YOUR COMPUTER NOT SUPPORT .NORM FILES? MAYBE YOU NEED TO UPDATE.
SINCE EVERYONE SENDS STUFF THIS WAY ANYWAY, WE SHOULD JUST FORMALIZE IT AS A STANDARD.

