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

Stephan Devriese
replace measure with routinely collected data

use routinely collected data for otherwise unavailable measure

clinical trial

aggregated or individual
assumptions

access

privacy

proportionality

finality

technology
where to find registries?
the unusual suspects

ICT

colleagues

EPD

accountancy
F A I R

- Findable
- Accessible
- Interoperable
- Reusable
https://fair.healthdata.be/global-search?q(source_label):"Metadata"
- 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

www.zorg-en-gezondheid.be

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

sante.wallonie.be

www.dg.be
a selection of organisations
data flow

patient → sickness funds →

health care professional in hospital
### 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
- Foodborne 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

Health status of the Belgian population
Read more ...

Health System Performance Assessment
Read more ...

Patterns of variations in medical practices
Read more ...
<table>
<thead>
<tr>
<th>quality &amp; organization</th>
<th>data management</th>
<th>hospital financing</th>
</tr>
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<tbody>
<tr>
<td>• StatHosp</td>
<td>• MZG – RHM</td>
<td>• FINHOSTA</td>
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<td>• Colleges</td>
<td>• MPG – RPM</td>
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<td>• Pain</td>
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<td>• Clinical pharmacy</td>
<td>• Medical imagery</td>
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<td>• SDD – IHAB</td>
<td>• Hospital characteristics</td>
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<td>• P4P</td>
<td>• …</td>
<td>• …</td>
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<tr>
<td>• Patient security</td>
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population

- socio-demographic data
- insurance status
- social benefits
- ...

pharmanet

- reimbursement data
- pharmaceutical products dispensed in public pharmacies
- ...

health

- reimbursement data
- health care
- ...

Intermutualistisch Agentschap
Agence Intermutualiste
<table>
<thead>
<tr>
<th><strong>BCR</strong></th>
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<td>• subset of reimbursement data</td>
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<td>• subset of population data</td>
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</table>
### Authentic Sources
- nomenclature
- reimbursed pharmaceutical products
- implants
- regulations
- ...

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

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**RIZIV–INAMI**

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[www.kce.fgov.be](http://www.kce.fgov.be)
Informatieveiligheidscomité
Comité de sécurité de l’information

IVC–CSI

chamber Federal Government
residuary competence

chamber Social Security and Health
authorising competence
- Trusted Third Party services
- Connector projects to various registers
- Referral repertory
- ...

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

access
quality of registration

register dependent

on site audit

data driven

fair.healthdata.be

data quality section + reports:
  • validity
  • reliability
  • timeliness
  • precision
  • integrity

use in other research
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.