Health-RI: Empowering Personalised Medicine and Health Research in the Netherlands

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SELL
THE PROBLEM
YOU SOLVE,
NOT THE
PRODUCT.
Why Health-RI?

research  care

innovation
The underlying problem...

FRAGMENTATION of...

- data
- sample collections
- image collections
- regulations
- software tools
- research initiatives
- funding
- expertise
- etc.
researchers want hassle-free research...
.... and patients want fast innovation

TRANSLATIONAL
BIOMARKER TEST.

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Translating Data to Health

Workshop: 21 - 25 March 2016, Leiden, the Netherlands

Scientific Organizers
- Niklas Blomberg, ELIXIR Hinxton
- Jan-Willem Bolen, Lygature Eindhoven
- Scott Lusher, Johnson & Johnson Beerse
- Gerrit Meijer, NIO Amsterdam

Topics
- One Patient - One Petabyte
- Rethinking Data-Driven Translational Research
- Crossing the Research-Clinical Care Line
- Social & Regulatory Aspects
- FAIR Data Sharing

Social!

The Lorentz Center is an initiative of the Netherlands Organisation for Scientific Research. Its aim is to organize high-quality, collaborative work, discussions and educational activities. For registration, see www.lorentzcenter.nl
Internet of Personalized Medicine & Health Data & Things

- Biobanks, cohorts
- Wearables
- MRI center
- Research laboratory
- Twitter data
- Clinical records
- Microscopy facility
Health-RI services and activities lead to an infrastructure that facilitates the research process

The infrastructure set up by Health-RI facilitates the different steps in the research process (non-exhausting) by providing:

**Level of services and activities**

<table>
<thead>
<tr>
<th>Operational level (platform services)</th>
<th>Tactical level (connecting the network)</th>
<th>Strategical level (transforming the system)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Define research question</td>
<td>FAIR data management training, education and support</td>
<td>Increasing citizen participation</td>
</tr>
<tr>
<td>Experimental design</td>
<td>Compliance tools and legislation, Biobanking registry support center</td>
<td>Promotion of the transformation to registration at the source in healthcare, Promotion of omnibus legislations</td>
</tr>
<tr>
<td>Access to data and samples</td>
<td>Central catalogue and request tool for data, samples and images</td>
<td>Promotion of the opening up of industry trial data, Promotion of all data to be available in the public domain</td>
</tr>
<tr>
<td>Data generation</td>
<td>Catalogue of facilities &amp; expertise centers, Interoperable data acquisition tools</td>
<td>Coordination of investments in data infrastructures via the financing agenda, resulting in sustainable long-term funding</td>
</tr>
<tr>
<td>Analysis</td>
<td>Interoperable analysis tools, Federated analysis workspace, Helpdesk IT-tools and services</td>
<td>Coordination of investments in IT tools and facilities infrastructures via the financing agenda, resulting in sustainable long-term funding</td>
</tr>
<tr>
<td>Translation and dissemination</td>
<td>FAIRifier tools, Data stewardship training</td>
<td>Promotion of active data sharing and open science policy</td>
</tr>
<tr>
<td>Improvement of research / care</td>
<td>Researcher-participant interaction App</td>
<td>Promotion of learning care system</td>
</tr>
</tbody>
</table>

**Research Continuum**

- **Define research question**
- **Experimental design**
- **Access to data and samples**
- **Data generation**
- **Analysis**
- **Translation and dissemination**
- **Improvement of research / care**

The Health-RI platform offers researchers solutions on demand for each step of the research process. By simultaneously operating on tactical and strategic level, Health-RI connects the needs of researchers and other stakeholders (funders, society, etc.) transforming the total personalized medicine & health research system.
Operational shared services

- Catalogue
  - data
    - phenotype
    - omics
    - wearables
  - images
  - samples
- ELSI services
  - compliance by design to regulations
    - privacy
    - influencing legislation
  - mybiobank etc
- IT services
  - standardisation
  - online digital research environment
    - “office 365” for personalized medicine & health research
  - interfacing to advanced technologies
    - deep learning pipelines for image analysis
    - multi-omics pipelines
    - etc
- Personalized Medicine Research Process Management
“Doc, it’s the best thing since fire: the Engraved Health Record. Our EHR is portable, durable, and fully compatible with other systems.”
Ideal world: direct link between EHR & research domains

Care data environment

- Minimale data sets geimplementeerd

PSI
Parelsnoer Institute

Clinical studies
Patient-reported

Pseudonymisatie
QA/QC

Registration data portal

Catalogue

Any researcher

4) Downstream

Metadata

Data access committee

Any researcher

request
Interim solution 1: Proxys

- QA registry
- Drug registry
- PALGA

EHR
- Local data warehouse
- HIS

Proxy
- Local data warehouse
- Registry
- eCRF
- Research datamart
- Genomics data, etc
- Research DB’s

Pseudonymization
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<th>Materiaal</th>
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<th>Vrouw</th>
<th>Aantal excerpten</th>
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</tbody>
</table>
structured reporting
Dutch National Tissuebank Portal

“web shop” for ordering from
- 12 Mio tissue blocks
- 30 Mio records
- increasingly structured reports
back office workflow
- on top of PALGA database
- research <> 50 pathology labs
- track & trace
- QA
interim solution 2:
rescue manual curation efforts

clinical trials

cohort studies

retrospective studies
“Office 365” for translational research
Health-RI biosample applications

BBMRI Biosample Catalogue

Palga Public Database

Dutch National Tissue Portal
The trick: apply FAIR to best practices

- BBMRI-NL catalogue (Findable, Accessible)
- Parelsnoer PRISMA data model
- Request portal DNTP developed for PALGA
- ELSI support center BBMRI-NL & COREON
- Molgenis & tranSMART portals for downstream analysis
- cBioportal for intuitive visualisation
- Minimal data sets: Registration at the Source, involving medical associations
- Quality assurance & process optimization: EATRIS
- Standardize ETL between large registries (NKR-oncology; NHR-cardiology, etc.)
- FAIRification expertise: DTL/ELIXIR-NL
- Digital Research Environment Data4lifesciences/ELIXIR
- Harmonized organization of institutional back offices D4LS
- Effective helpdesk for end users
Endorsed by stakeholders, and the people behind these