Realising the Value from Health Data ~ Improving Care and Research

Annual Conference 2017

Realising Value from Health Data for Improving Care and Research

i~HD / EMIF Joint Conference - Opening Address

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Vice-Directorate General of Healthcare Information and Evaluation

Health Data: some top-down visions

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How can we help you?

• How can we contribute to Realising Value from Health Data for Improving Care and Research
  • We are working within a Ministry of Health
  • We have learned to draw our top-down vision
  • Now we really need to match bottom-up visions and use cases
  • Secondary uses of Health Data: a huge source of improvement
  • Impact of conflicting business models related to health data?
    • Free text vs structured encoded content: a matter of balance and extracts
    • Value extraction roles: data processing vs knowledge acquisition
• The Lifeline Vision: interoperability for every citizen’s lifespan
  • Cohorts identification is now feasible
  • Personal data dissociation & anonymization help prevent illegitimate use
  • Learning how to respect preferences of individuals and social groups
  • Disease, information and time may change preferences
Some practical approaches

- **Staged** approaches to Health Data sharing in Spain
  - *National Citizen/Patient Identification has been a key factor*
  - *SNOMED International Membership since 2009*
  - *Connected secure communications infrastructure*
  - *Careful attention to standards including W3C, IHE, CEN, ISO and HL7*
  - *Quick delivery of Exchange*
    - Relevant *healthcare* data content: 78% done
  - *Careful planning for genuine interoperability based on standards*
  - *Deep interoperability of Health Data needs decentralized efforts*

- *Deep* = technical, syntactic, semantic***, organizational, legal, cognitive [defined], ...
Some methodologies & tools

• Clinical Information Modeling methodology (*plus* tools)
  • Modeling in 3 steps
  • Terminology binding made easy, understandable and accessible

• SNOMED CT® International & Spanish editions, plus ...

• SNOMED CT® National Extension for Spain ***
  • General extension concepts n = 4.000
  • Medicines extension *** (in collaboration with AEMPS [Agency])
    • VTM n = 2.000
    • VMP n = 5.500
    • VMPP n = 8.000
    • Maps (actual products-concepts) n = 26.000
  • Procedures classification (ICD-10-PCS)
    • Mapping Project in collaboration with US [NLM], BE [NIHDI], AR, IHTSDO

Links
• HCDSNS System
• HCDSNS Status
• ePrescription interoperability
• SNOMED International
Setting the stage

• Secondary uses of Health Data:
  • Preserve confidentiality + optimize Health Data usage
  • Adopting a code of conduct may make a difference
  • Key persons/roles selected and appointed:
    • data controllers, data processors, data protection delegate
  • Audit secondary uses as a normal thing
  • Use consent as and whenever required

• Personal Data Protection Regulations
  • Study challenges thoroughly
  • Identify opportunities and synergies
  • Deal with organization’s weaknesses
  • Identify, build and develop your strengths

Links
  • HCDSNS System
  • HCDSNS Status
  • ePrescription interoperability
  • SNOMED International
  • Regulation 2016/679
A more friendly data environment for healthcare and research

Refinement of Information Objects

<table>
<thead>
<tr>
<th>Population eID</th>
<th>Primary sources EHR</th>
<th>EHR Extracts XML, JSON</th>
<th>Aggregates .xls, HTML</th>
<th>Indicators PDF</th>
</tr>
</thead>
</table>

- Health Id Card
- Confidentiality Fragmentation Non-interoperability
- Consensus
- Masking of small n
- Adequate denominators
- Consent
- Timescale
- Lifeline
Additional help is available

- SNOMED CT Reference Implementation as a Data Base ***
  - Quick deployment for implementors and services
- Exhaustive study of Personal Data Protection regulations
  - REGULATION (EU) 2016/679 ***
  - Derived legislative projects
- Participation in events dealing with...
  - Secondary Uses of Health Data
  - Requirements for interoperability of Electronic Health Records
  - Open ontologies development
- Training, tutorship, promotion ***
- Project collaboration & support
- Ontology of Healthcare Centers and interoperability levels

Links

- Semantic resources
Shared Platform is needed

Knowledge Formal Representation

Direct Care Data

Legal coverage

Secondary Use Operations

Personal Data Protection

EHR Extracts Generation

How the future looks like

Centralized

Decentralized
Sincere thanks!
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