Plateforme Apprenante pour la recherche en santé et services sociaux (PARS3)

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Overview

1. Multiple requirements:
   - Care delivery
   - Knowledge transfer (ex: decision support)
   - Research

2. Learning Health Systems

3. Similar Challenges:
   - Heterogeneous sources
   - Distributed sources

3. Data access in context of LHS
   - PARS3
   - Open source, secure distributed
   - Ontology to relational schema

4. Ethical framework

Requirements and Learning Health Systems
Is it only about more data?
**Silos**

- **Care delivery**
  - Incomplete information
  - Incomplete knowledge
  - Suboptimal care

- **Decision support**
  - Pertinence
  - Context
  - Prevalence

- **Research**
  - High costs
  - Difficult recruitment
  - No validation
  - Piece meal data access
  - Limited knowledge transfer

**Learning Health System (LHS)**

- First glimpses in the mid 2000's
  - JM McGinnis and C. Friedman
  - IOM 2007

- *The Learning Healthcare System (LHCS) refers to the close coupling of practice of clinical medicine with both the conduct of research and the translation of research into practice.*
Feasibility studies

- Before extracting data:
  - Enough subjects?
  - Required data elements?

- Retrospective and prospective studies
  - Especially for rare diseases or primary care (multiple small, fragmented sites)
Retrospective studies

- Using clinical, medico-administrative and genomic data
  - In some cases, avoid the need of cohorts
  - Reflecting what happens in « real » life
  - Executed in multiple countries in parallel for better generalisability

Prospective studies

- Semi-automated identification of potentially eligible subjects
- Pre-filling research forms (67%)
  - More efficient, more complete (memory bias)
Care delivery using research data

- Returning research data to care
  - A patient presents with a complaint of pulmonary embolism
  - HTA: clinical inertia

The NEW ENGLAND JOURNAL of MEDICINE

Electronic Health Records, Medical Research, and the Tower of Babel
Rebecca D. Kush, Ph.D., Edward Helton, Ph.D., Frank W. Rockhold, Ph.D., and C. David Hardison, Ph.D.

NEJM 2008

New hypotheses

- «To demonstrate the biological use of these new resources, we used them to [...] discover drug class interactions. We then corroborated 47 ($P < 0.0001$) of the drug class interactions using an independent analysis of electronic medical records.»

- «Our analysis suggests that combined treatment with selective serotonin reuptake inhibitors and thiazides is associated with significantly increased incidence of prolonged QT intervals.»

RESEARCH ARTICLE

CLINICAL DATA ANALYSIS

Data-Driven Prediction of Drug Effects and Interactions
Nicholas P. Tatone1,2, Patrick P. Ye3, Roxana Daneshjou1, Russ B. Altman1,2
Sci Transl Med 2012
Metformin and cancer

Hypothesis: The association between metformin and cancer, if present, should be easily detectable using routine care data.

CONSEQUENCE:
CARE DELIVERY, RESEARCH AND KNOWLEDGE TRANSFER MUST BE TIGHTLY COUPLED
DATA
WHICH ONES? WHERE?

Information Challenge: Fragmentation

- Clinics
- Hospitals
- Social care
- Health Ministry
- RAMQ/ISQ

- Fitbit
- Smart phone
- Home automation (ex: thermostat)

- Cohort
- RCT
- Biobank
- Excel spreadsheets

- SMOG reports
- Water Quality reports
Quantified self: SCI FI?

- A physician and a bracelet: together for the win
- September 2016

Interrogation of Patient Smartphone Activity Tracker to Assist Arrhythmia Management

Jessica Richardson, DO, Scott McDougall, MDN, APN-C, John Selzer, MD, Marvin Smith, DO, Alfred Badami, MD, PhD
**Paradigm Shift**

- **Present**: focus on data warehousing – institution centered
  - Interesting successes

- But…
  - Not all information will ever live in the same institution
  - Nor in the same system

- **Future**: Distributed systems – **citizen centered**
  - Better understanding of each individual
    - Precision medicine
  - Collaboration (provincial, national… or simply between two clinics using different EMRs)
  - Use data where it lives (and is kept up to date)

**PARS3**

LEARNING HEALTH AND SOCIAL SERVICES RESEARCH PLATFORM
TRANSFoRm

- 2011-2016
  - ~ 10 million euros from EU

- Observational
  - Clinico-genomic | Diabetes

- Decision support
  - three common presenting complaints

- RCT
  - Antacid daily vs on demand
  - 4 countries
  - 5 EMRs
  - 3 languages
Vision

- Production ready system to be used with a wide variety of data with the following attributes
  - Security
  - Quality
  - Ethics, transparency, consent
  - Research standards
  - Sharing of resources

- Identifying and mapping data once for reuse in multiple projects / platforms / context / activities
- Easy, discoverable data dictionary emerging from the previous step
- Enabling virtual access and distributed analysis on a per project basis
- Minimising the amount of data be extracted from sources

Project based

- Project plan
  - Participants
  - Workflow
  - Queries

- Signature from everyone REQUIRED before execution
Principles

- An open ecosystem with interchangeable components where multiple versions can coexist.
- Users: patients, clinicians, researchers, administrators…

- Automated workflow execution

- Data functions
  - Identifying where is located the required data (if available)
  - Identifying a target population
  - Extracting data
    - From multiple sources
    - From common “ontological” queries

Principles (2)

- Minimising the necessity to know the technological characteristics and architecture of the source

- Minimising the resources to
  - Get on board
  - Maintain participation over time

- Support multiple platforms
Principles (3)

- Authorisations
  - Minimising subjectivity in decision
  - Make the process predictable
  - Minimising treatment time

- Data
  - Quality exploration
  - Harmonized format on return

Mediation

- Ontology based
  - Used to issue queries and to generate target relational model
  - OBO Foundry

- Mapping only once at the structural level
  - Terminologies as necessary

- Linkage to support multiple sources
ONTOMETRY TO RELATIONAL SCHEMA

Requirements

- Scalability and performance at a national level
- Temporalization
  - Limitation of data exposure in the mediation system
    - Minimizing data being transmitted for evaluation of suitable subjects
  - Presenting data as a relational database
    - Expectations of users and tools
- Facilitating translation to triples at destination
- Ensuring a coherent and shared view of the domain
- Offering all the required information to ensure use of data outside its native environment
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Deployment types (Russian dolls) – PASS architecture core

- **Local**
  - Generating and feeding a data warehouse

- **Distributed regional access**
  - Extraction on a per project basis. Secured infrastructure offered to receive data.
  - Example: PARS3 Québec

- **Distributed and decentralised data access and analysis**
  - Regional (provincial) hubs. Parallel extraction and analyses with tools like Data Shield (Maelstrom Research)
  - Example: SPOR National Data Platform (which we can’t talk about!)

**CONSEQUENCE**

WE NEED TO FACILITATE AND UNIFY DATA ACCESS OPERATIONS… WHILE ALLOWING LOCAL STRENGTHS TO SHINE
ETHICS AND THE LHS

EACH PROJECT MUST HAVE A CLEAR AND CONCRETE KNOWLEDGE TRANSFER PLAN

Social contract for LHS:
3 principles

- Engagement
  - Care givers, patients, stakeholders, clinicians, researchers

- Transparency
  - Good communication about what is happening on the platform
  - Patient specific information on contribution

- Responsibility
  - Plan and demonstrate care improvement and ideally through PROM/PREM

Framework

- Scare littérature. One proposal:
  1. Respect the rights and dignity of patients
  2. Respect clinician judgments
  3. Provide optimal clinical care to each patient
  4. Avoid imposing nonclinical risks and burdens on patients
  5. Address health inequalities
  6. Conduct continuous learning activities that improve the quality of clinical care and health care systems
  7. Contribute to the common purpose of improving the quality and value of clinical care and health care systems


Consent: really patient centered?

- Obligation of knowledge transfer
  - Changing the balance of autonomy versus social beneficence?

- Consent based on patient desires instead of being fixed project wide? [engagement, autonomy]
  - Metaconsent
  - Consent portal

- Transparence citizen portal to have access to how your data was used by projects [transparency, responsibility]
PARS3 Partners

**Development**
- EMR Vendors
- PRHDN – SPOR National data platform
- Biden Cancer Initiative (USA)
- HEGP, Paris
- University of Dundee
- Maelstrom Research
- CIUSSS de l’Estrie-CHUS
- University of British-Colombia

**Users**
- GMF-U Richelieu-Yamaska, …
- CIUSSS de l’Estrie – CHUS
- Sentinel Québec
- Réseau I Québec
- Réseau SRAP Diabète Action Canada
- Réseau FRQS de recherche sur la douleur
- CARTaGENE
- Ministère de la santé et services sociaux du Québec
Summary

1. Research must be part of integrated system
   - Shared requirements, shared data
   - Most complete and unified vision of an individual

2. Data required by research comes varied and sources
   - Large perimeter
   - Significant heterogeneity

3. Reuse whenever possible instead of duplicating.

4. A social contract is essential

Thank you

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