International Medical Informatics Association’s

Transnational Health Data Reuse Initiative
Steering Committee
(2012)

- **Riccardo Belazzi**, Professor of Bioengineering and Medical Informatics, Dipartimento di Informatica e Sistemistica, University of Pavia
- **Iain Buchan**, Director NIBHI & NWeH Science, University of Manchester
- **Georges DeMoor**, President of European Institute for Health Records
- **Antoine Geissbuhler**, President at International Medical Informatics Association (IMIA)
- **Steven Labkoff**, Head of Strategic Programs at AstraZeneca Pharmaceuticals
- **Peter Murray**, CEO International Medical Informatics Association (IMIA)
- **Julian Remnant**, Partner, R&D Advisory at Deloitte Europe
- **Craig Richardson**, Head of Access to External Data at Janssen Pharmaceuticals
- **Charles Safran**, Associate Professor of Medicine Harvard Medical School, Past President & Chairman, American Medical Informatics Association
- **Eric Silfen**, Senior Vice-President and Chief Medical Officer at Philips Healthcare
- **Mats Sundgren**, Coordinator for Innovative Medicines Initiative EHR4CR project
- **Karin-Marie Tretter**, Vice President Medicine and Nurse Care at Siemens Medical Solutions GSD GmbH
European Context

- According to the United Nations, the population within the standard physical geographical boundaries is about 720 million using the definition which has been used for centuries. The European Union (E.U.) population is about 500 million.
- There are 27 E.U.- Member States and each is responsible for its own National Health System (cf. subsidiarity principle).
- There is no central Health Authority in Europe.
- There are 23 official languages of the European Union. The most widely spoken mother tongue in the EU is German, while 51% of adults can understand English.
- The eHealth market is highly fragmented (e.g. over 900 EHR system vendors).
Current State

- European countries
  - Collect large amounts of healthcare data
  - Have a rich variety of health environments and care settings
  - Have a tradition of registry-based epidemiology
  - Do not have a common framework for research with healthcare data
  - Do not make it easy for companies to access and work across the data sources
Primary Care Practices

• 87% primary care practices use computers
  – 69% have Internet access
  – 57% send or receive patient identifiable data
  – 50% obtain patient consent to store or transmit data
  – 24% exchange email with patients
  – 9% transmit prescriptions to pharmacist
  – 4% offer some form of telemedicine
Acute Hospitals

- 92% acute hospitals connected to broadband
  - 81% acute hospitals have EHR
  - 61% have PACS
  - 54% have wireless
  - 43% electronically exchange radiology reports
  - 20% use ePrescribing
  - 24% of EHR’s available to external providers
  - 8% telemonitor outpatients
  - 5% exchange clinical care information elsewhere in EU
  - 4% provide patients with access to EHR
2012 European Summit on Trustworthy Reuse of Health Data

• In recognition of the challenges associated with the reuse of health data, the International Medical Informatics Association hosted over 100 delegates convened in Brussels, Belgium in May, 2012 to discuss European and national policies that are influencing the trustworthy reuse of health data

• The agenda consisted of plenary speakers, panels, and working sessions designed to stimulate the sharing of diverse perspectives and generate output that could be used to design a European-centric framework for health data reuse

• The Summit was able to concentrate energy and focus on European-centric policies that are limiting the movement and use of health data
Trustworthy Reuse Impasse
Doing nothing is not an option

• 3 Ingredients
  – Data (tsunami); Models (blizzard); Expertise (drought)

• 3 Myths
  – Big data is the solution
  – Science provides the models to transform the data
  – Clinicians will continue to be the main source of data

• 3 Pipelines
  – Clinical Operations; Research; Payer & Governments
  – Fail to borrow strength from one another
This white paper summarizes the output and discussions that took place at the May 2012 Summit on Trustworthy Reuse of Health Data. It describes the approach and methodology used to bring together a group of stakeholders with diverse opinions about health data reuse, shares opportunities and challenges, and provides an outline for next steps.

This white paper was published in November, 2012 in the International Journal of Medical Informatics:  
This channel includes all of the 2012 Summit plenary sessions and several videos that summarize delegate’s perspectives regarding the trustworthy reuse of health data. As of December, 2012, the videos have been viewed over 1,800 times: http://www.youtube.com/user/EUSTRHD
This website provides an overview about the Summit and includes links to background materials, pre-reads, agenda, presentations, and recognizes the sponsors for their support: http://euhealthdata2012.imia.info
Conclusions of 2012 Summit

• Doing nothing will have negative implications across the EU.
• First, continued fragmented parallel non-standards-based developments entail a substantial duplication of costs and human effort.
• Second, a failure to work jointly across the stakeholders on common policy frameworks will forego a crucial opportunity to boost key EU markets (pharmaceuticals, health technology and devices, and eHealth solutions)
• Finally, and perhaps most importantly, the lack of harmonized policy across EU nations for trustworthy reuse of health data risks patient safety.
2013 Calendar

2013 European Summit on Trustworthy Reuse of Health Data
Brussels, Belgium

Initiative Steering Committee Meeting
Geneva, Switzerland

MEDINFO Panel presentation on health data reuse
MEDINFO Cocktail reception
Copenhagen, Denmark

Stakeholder’s Consultation at the WHO
Geneva, Switzerland

Policy discussion and lunch session at the 2013
WHO Assembly Meeting
Brussels, Belgium

Scientific discussion and lunch session at the
Science and Challenges meeting with WHO audience
Brussels, Belgium

eHealth Week
Dublin, Ireland
Reflections

• There is an ecosystem around data. Each transaction potentially creates value. Each transaction costs something and conversely creates revenue for someone.
• When we talk about the value of data we are most uncomfortable talking about the economic value of data.
• Government may be the largest consumer of data.
• We do a poor job communicating the issues of reuse of health data to our fellow citizens.
## 2012 Sponsors

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