Vision and Experiences of the European eHealth Platforms

Prof Dipak Kalra
President of i~HD
Treatment needs are changing

- There is a requirement for new, safer, more effective medicines

- Ageing Population
  - 1 in 9 ≥ 60
  - 1 in 5 by 2050

- Long-term chronic disease management
  - By 2030, 10% of European adults are predicted to have diabetes, compared with 8.5% in 2010²
  - By 2030, 22.2m new cases of cancer are expected to be diagnosed annually³
  - Number of people with dementia will nearly double every year⁴

- Diabetes
- CV
- COPD
- Asthma
- HIV/AIDS

- Mental disorders
Learning Health Systems

Clinical Care
- incident monitoring & detection
- outcome analysis
- retrieval of similar patient history
- care management patients at risk
- re-admission prevention
- diagnosis & treatment assistance

Clinical Research
- System biology
- Lead identification
- Biomarker definition
- Clinical trial Execution
- Market Access
- Ongoing safety tracking

Clinical Workflow
- Data Collection
- Decision support

Clinical Data
- Information

Research Workflow
- Data integration
- Data exploration

Medical Knowledge
- Knowledge
The German Medical Informatics Initiative

Goals

Innovative IT solutions to improve research & patient care
- starting at university hospitals & extending to smaller sites

Intensify the exchange and sharing of data
- between research and the health care delivery system

Re-establish medical informatics as a progressive field
- in research, teaching and continuing education

Set up data integration centers (DIC)
- to pool local data resources and network with other sites
MIRACUM Pilot Integration

Analysis of colorectal cancer cohort

Pilot Architecture

Source data
ETL
Data Repository
Queries
Federation

§21

IDRT
Talend

i2b2
OMOP

SQL
SQL

L-i2b2

Geovisualization of Catchment Area

11 Sites
3,3 Mio Patients
30 Mio Diagnoses
23 Mio Procedures

Analysis of colorectal cancer cohort

Slide from Thomas Ganslandt, MIRACUM: Sharing Data for a Learning Health System
Local EHRs and personal health data

Centralising layer

Information models, archetypes, ontologies

Patient and staff registries and authorisations

Access portals

Analysis repositories and tools
NHS (England) Target Architecture

Nationally pooled data for research

National patient and staff registries and authorisations

Regional hubs supporting: integrated care pathways, public health and service planning

Local EHRs and personal health data
The European Commission’s Digital Single Market strategy for
digital health and care (2017)

1. **Electronic health records**: secure access, possibility to share across borders; and the use of e-prescriptions.

2. **Data infrastructure**: to advance research, disease prevention and personalised health and care including rare diseases.

3. **Feedback and interaction between patients and healthcare providers**: to support prevention, citizen empowerment, quality and patient-centred care.
eHealth Digital Services

Core services:
- e-Identification
- e-Signature
- e-Delivery
- e-Invoicing
- cyber security
- eHealth services
  - open source platform
  - portals
  - semantic services

Generic services:
- national connectors to the core services
- national portals
- terminology translations

National/local services:
- eHealth systems and services that
  - export and import patient summaries
  - manage patient and user identification

European Commission

National health and care systems

x28
Potential multi-source revenues in the long term

VALUE PROPOSITIONS

1. Cross-border exchange of medical summaries for unplanned care
2. Cross-border co-operation for
   • rapid diagnosis, safe prescribing
   • improving health outcomes
   • increasing efficiency
3. Scale up adoption of interoperable eHealth and mHealth solutions
4. Scale up population level research

Source: VALUeHEALTH Project, 2017
Innovative Medicines Initiative: Europe’s partnership for health

Partnership 2008 - 2024

€2.5 bn

> €5 bn

€2.5 bn

Slide from Pierre Meulien, Executive Director of the Innovative Medicines Initiative
EMIF vision

To become the trusted European hub for health care data intelligence, enabling new insights into diseases and treatments

Slide courtesy of Bart Vannieuwenhuyse, Janssen
EMIF overview

ACADEMIC PARTNERS

SME PARTNERS

EFPIA PARTNERS

PATIENT ORGANISATION

57 European partners
€56 million of resources
5 year project

58 Partners
The EHR4CR project

- EHR4CR – Electronic Health Records for Clinical Research
  - 4+1 year project (2011-2016), 35 partners, budget >17M€

- Objectives & Scope
  - Provide a platform for **trustworthy re-use of EHR data** to support innovation in clinical research
  - Securely reusing **health data** for optimising clinical trials
  - 7 pilot sites across Europe

For more information: [http://www.ehr4cr.eu/](http://www.ehr4cr.eu/)
Patient recruitment a major cause of trial delays

The percentage of studies that complete enrolment on time:

- **18%** in Europe,
- **7%** in the US\(^1\)

Almost **half** of all trial delays caused by patient recruitment problems\(^2\)

Each day a drug is delayed from market, sponsors lose up to **$8m**\(^3\)

50% of today’s clinical trials fail to achieve the target recruitment rate\(^4\)
InSite – technical overview, for protocol feasibility

Custodix provides expertise and tools to support local sites with mappings.

Only aggregated data (patient counts) leave the hospital, only on approval.

EHR → ETL → CDW → Local Install

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Protected by Privacy Enhancing Techniques e.g. suppression of small counts.

Full audit trail inside hospital.

External governance by i~HD.

Secure access for researchers.
InSite – Protocol feasibility query

Patient results have been obfuscated for sites MCW. Approximated results are indicated by an * icon.

Patient Reach for Baseline query

58* PATIENTS

34* NETHERLANDS

34* MCW

Site & Country Scores

Patient matches per country

Netherlands: [16,52] United Kingdom: 24

Patient matches per site

MCW: [16,52] EHHT: 24
“A multi-stakeholder collaboration aiming to accelerate and ensure the future of clinical research in Europe.”
A convergence of opportunity

Clinical Research
- Enhance access to Real World Data
- Optimise clinical research processes
- Generate new evidence for precision medicine and value based care

Healthcare
- Improve quality and safety of care
- Support patients in self-care and health maintenance
- Improve efficiency of care

Need to improve access to combined health data from multiple sources
Common challenges to the use of health data for person centred care, and the re-use of health data for clinical research

Privacy protection, ethics and security
accessing data

Quality and interoperability of health data
learning from the data

Demonstrating value
transforming healthcare
The European Institute for Innovation through Health Data (i~HD) is registered in Belgium as a not-for-profit organisation. It is being financed by membership fees, by providing services such as certification and governance and through specifically-funded projects and initiatives.

i~HD has been formed as one of the key sustainable entities arising from the EHR4CR and SemanticHealthNet projects, in collaboration with several other European projects and initiatives supported by the European Commission. To guide and catalyse the best, most efficient and trustworthy uses of health data and interoperability, for optimising health and knowledge discovery.
Assuring public trust when reusing EHRs for research

- Compliance with data protection legislation, at a European level and across all European Member States
- Greater confidence and reduced risk
  - for those providing data for research use e.g. hospitals, GPs, patients
  - for those performing the research, managing the data or sponsoring the research
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i~HD information governance priorities

...building on the GDPR and the IMI code of practice on secondary use of medical data in scientific research projects...

Principles and Standard Operating Rules for using federated research platforms

- Educate and train research and ICT staff
- Accredit staff and organisations
- Certify service providers and EHR systems
- Oversee and audit governance & security

RESEARCH SPONSOR

ICT SOLUTION PROVIDERS

CARE/RESEARCH ORGANISATIONS

- Data Provider
- Data Provider

CLINICAL RESEARCH PLATFORMS

APPLICATION PROVIDERS

OTHER DATA AGGREGATORS

RESEARCH USER

RESEARCH SPONSOR

RESEARCH USER

Network Providers

Essential needs for interoperability

- Guideline and decision support systems need to process **integrated health data** drawn from **multiple EHR systems** in a **consistent way**
- Intelligent **personal health systems** need to centre care on patients
- Health services, insurers and public health bodies need **fine grained activity and outcome data** to optimise services
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i~HD semantic interoperability priorities

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- Quality processes for clinical information models and terminology value sets
- A quality labelled online register of interoperability assets
- Promoting adoption of interoperability standards and profiles
i~HD Data Quality Taskforce aims

- Develop data quality assessment methods, tools and improvement strategies to maximise quality of health data
- Promote the importance of data quality, to hospitals and other stakeholders

Focus quality for:
- healthcare
- clinical trials
- big data research

Slide courtesy of Pascal Coorevits, Ghent University & EuroRec and Carlos Sáez, Universitat Politècnica de València
Demonstrating value from the use of health data

Evaluate the benefits of using health data on a large scale:
- outcomes evidence to improve care
- faster and more efficient clinical research
- better information for public health decisions

Value to healthcare

Value to patients and to society

Value to research

Grow a Network of Excellence

Promote and collaborate globally
Enriching knowledge and enhancing care through health data
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Adapted from Tapani Piha, Head of Unit, Cross-Border Healthcare and eHealth
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Finished results for Baseline query
Reference date: Apr 21, 2012

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Site & Country Matches

[Diagram showing patient matches per country and site]
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Targeting hospitals in Belgium, Germany, Finland, France, Italy, Netherlands, Poland, Spain, Switzerland, Sweden, and US
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