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European Institute for Innovation Through Health Data (i~HD)



Prof. Georges De Moor

Member of the Editorial Board IT

*****@***ugent.be

Head of Department - State
University of Ghent, Eurorec
Department of Health
Informatics and Medical
Statistics

A new not-for-profit organisation, the European Institute for Innovation through Health Data (i~HD), held its inaugural conference and public launch in March this year in Paris.

This institute was formed in order to unite efforts to enable better uses of health data for the benefit of learning health systems and clinical research (The European Institute For Innovation Through Health Data, 2015). Healthcare organisations, health ministries and insurers, public health bodies, academic and industry sponsored research all recognise the potential opportunities to learn more from the growing volumes of health data collected in care settings and by patients themselves. The knowledge gained can be applied to optimise care pathways, improve the effectiveness and safety of the treatments given to individual patients, enrich our understanding of the safety of new treatments and help focus healthcare systems towards maximising outcomes most effectively.

However, there are a number of road-blocks that limit our capacity to integrate at scale, and to analyse, large volumes of routinely collected health information. The most significant of these are:

- Concerns to ensure the protection of patient privacy;
- Poor interoperability of health information held within multiple different electronic health record systems, disease registries, claims databases and other public health repositories;
- Weak incentives for busy clinicians to document high quality structured and coded health information;
- A generally limited understanding within society of why patients and the public should support better usage of their personal health information.

The projects, initiatives, standards and incentives making efforts to tackle these issues are relatively fragmented, poorly understood and not well adopted. i~HD is working to bring together the relevant experts and initiatives to consolidate and further advance the enabling solutions vitally needed to address each of these issues, and to widely promote their adoption, with the aim of scaling up our collective capability across Europe of making better uses of health data, to advance knowledge and enrich healthcare.

European Overview

The inaugural conference brought together over 200 such experts from across Europe, including health ministries, insurers, the pharma industry, healthcare providers, patient associations, health professional associations, the health ICT industry and standards bodies. Participants learned about why enabling better use of health data is a key target of the French Ministry of Health, which is keen to see greater value derived from national investments in ICT, and regards the reuse of clinical data for research as of strategic importance. The Executive Director of the Innovative Medicines Initiative (IMI) (Innovative Medicines Initiative, 2016), which is investing over 5 billion euros in public-private research projects, emphasised the ambition of improving the affordability and speed of access to innovations for patients. IMI projects are using electronic health records to speed up clinical trials and using Big Data to discover how to better target innovative therapies to the particular patients who will respond best to them. Its new Big Data for Better Outcomes programme will also work closely with health care stakeholders to help apply new

evidence emerging from big data to improve healthcare systems. Participants also learned about Europe's largest "big data" project in health: European Medical Information Framework (EMI F, funded by IMI).

A policy officer from the European Commission, DG CONNECT, emphasised the importance that the EC places on improving the interoperability of health data, and empowering citizens to play a greater role in their own health care and wellness (The Digital Single Market, 2015). The EC is investing, through its Horizon 2020 programme, in many initiatives to improve information connectivity across healthcare systems, to provide citizens with great assurances about the privacy protection and trustworthiness of personal health applications and devices, and to tackle the particular healthcare challenges of an ageing society (eHealth and Ageing, 2015). A former hospital CEO speaker explained why hospitals need to gain better value from the health data that they collect, and therefore to ensure the ICT systems that they procure are of a quality that can support the organisation to optimise its performance in delivering patient-centred care, maximising outcomes as well as business efficiently. The EuroRec Institute plays this leading role within Europe, assessing and certifying the quality of health ICT products such as HER systems and clinical research platforms.

Innovative Directions

This inaugural conference also marked the parallel launch of a novel European platform to support multi-centre clinical research. This operational platform, called InSite, is the result of several European projects and connects securely to the data within multiple hospital EHR systems and clinical data warehouses across Europe, to enable a trial sponsor to predict the number of eligible patients for a candidate clinical trial protocol, to assess its feasibility and to locate the most relevant hospital sites.

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The role of i~HD, as a not-for-profit Institute, is to provide independent governance oversight of such clinical research platforms and services, as these expand to connect with multiple hospitals across Europe. Several presentations were given on this theme: the IMI-sponsored EHR 4CR project (De Moor et al, 2015) and its pharma-led adoption programme, the new legal landscape protecting patient privacy, and the i~HD governance services that reflect state-of-the-art in the trustworthy reuse of health data for research. An expert on health information law explained the new European General Data Protection Regulation (Reform of EU data protection rules, 2015) and its potential implications for clinical research and the integration of Big Data.

Also in the conference spotlight were the challenges and state-of-the-art approaches to improving the quality and semantic interoperability of clinical data, which was discussed within a panel comprising health ministry, health insurance, clinician and patient perspectives. The panel emphasised that interoperability is vital to ensure the coordination of care, especially because of increasing co-morbidity, with older generation patients having multiple long-term conditions and multiple treatments that can interact, potentially dangerously, unless care providers have the complete picture on their patients. There is a discord between the actors who use health ICT systems to record information, the actors who want to make use of that information, and those who invest in the ICT systems and thereby determine what is purchased, something that a new Horizon 2020 project VALUeHEALTH is investigating (The VALUeHEALTH Project, 2015). There was a consensus among the panellists that today's ICT systems demonstrate poor connectivity and poor patient orientation, and that many applications in use are not particularly friendly to the language and workflows of clinicians and patients.

The panelists emphasised the importance of making better use of interoperability standards, and declared that the key actors to drive that adoption are the public authorities and health insurance. They also emphasised that there should be better cooperative design of ICT solutions with end users. The audience were informed that i~HD is playing a growing role in the development and quality labelling of interoperability specifications, bringing together clinical and research domain experts, with patients, to help ensure that future standards will support patient care, learning health systems and clinical research.

Patient Perspective

Two of the conference speakers specifically represented the views of patients and of society. Patients are increasingly involved in the collection of their own health data, for example through monitoring devices, but do not always have access to their own data. They must be much more involved in how their health data are used to inform decision-making, and in those care and treatment decisions themselves. Society needs to be much more committed to promoting wellness and accelerating the discovery and testing of innovative treatments. Our ageing society is accumulating long-term conditions, and we need to be much more proactive in prevention and early detection. Health data are vital to improving our understanding of disease and the impact on the lives and wellbeing of patients. Society needs to better trust the security measures that can nowadays be applied to protect privacy, and to recognise the balance in proportionality between safeguarding health data and putting health data to good use.

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i~HD will continue to work on the development of best practices to promote a trustworthy ecosystem for reusing health data for research, and the adoption of standards for high quality and interoperable health data. i~HD will be working with patient associations to understand their views on societally acceptable ways to scale up learning from health data, and how such learning can also ensure patient involvement and empowerment.

Key Points

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- A new European not-for-profit Institute, i~HD, has been launched to unite efforts to enable better uses of health data, for the benefit of learning health systems and clinical research.
- i~HD will help to establish and propagate best practices in the protection of patient privacy when health data are used for research and for population health analysis.
- It will work with standards development organisations, clinical and patient communities and with research sponsors in order to ensure that future interoperability standards optimally support patient care, learning health systems and clinical research needs.
- i~HD will connect with patient associations to help to promote patient access to health data, patient engagement in the creation and use of health data, and patient empowerment in decision-making.

The conference was kindly hosted by the Assistance Publique - Hôpitaux de Paris & UPMC (Sorbonne Université) and organised by i~HD, EuroRec and RAMIT .

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