RDA Health Data Interest Group Second TC Agenda

21 Feb. 2017, 5pm (CET)

TC Agenda

- **Initiatives and sessions involving HDIG at P9 in Barcelona, 5-7 April 2017** *(topics of the sessions)*:

1. **IG HEALTH DATA** (Thur 6 April – h.14-15.30)

2. **BoF on Health Data and Blockchain** (Fri 7 April - h.9-10.30)

3. **Joint IG Big Data and IG Health Data** (Thur 6 April h.11.30-13.00)

- **Other ongoing activities: mapping the Health data domain** *(presentation by Leslie McIntosh)*

1. IG HEALTH DATA (Thur 6 April – h 14-15.30)

Meaningful health data for research and for industry

The objectives of the forthcoming Barcelona meeting are:
• Assessing the differences between US, Australia and EU regulation of health data, especially with regard to anonymised and pseudonymised data as well as to scientific usage.
• Mapping existing practical policies, relevant projects, and experiences related to health data, in view of prioritizing further issues and activities the IG will engage in
• Identifying other groups' activities
• Considering the value of industry participation in health data and discussing how to engage partners from industry in the HD-IG.

Meeting agenda
(moderation: Edwin Morley-Fletcher, President of Lynkeus)

1. Short introduction recalling the precursor sessions (P6, P7, P8), issues description (**Yannis Ioannidis**, President and General Director of the ATHENA Research and Innovation Center) [10 minutes]

2. Panel on how to define anonymization and pseudonymization of Health Data and requirements of Open Science (**Rocco Panetta**, Partner, Head of Privacy & IT Compliance Department at NCTM Legal Firm and **Jonathan Tedds**, Senior Research Fellow in Health and Research Data Informatics in the Department of Health Sciences at the University of Leicester) [30 minutes]

3. Further in-depth themes sprouting from Health Data: participants' presentations of some relevant projects and experiences (*data provenance, data comparability and data traceability in biotechnology*, **Joerg Geiger**, Manager systems biology and biobanking at University of Wuerzburg); *mapping ongoing initiatives in the Health Data domain and EU Commission perspective* (**Leslie D. McIntosh**, Professor of Health Informatics at Washington University School of Medicine; **Ellas Papadopoulou**, Legal Officer European Commission DG RTD, DIR "E-Health"); *Drag-in industry participation* (**Spyro Mousses***, PhD CHOC Children's Hospital of Orange County), *other speakers* submitting topics and slides [30 minutes]

4. General discussion and wrap-up [20 minutes]

Short contributions with 1-2 slides are welcome; please notify the organizers Yannis Ioannidis, Anthony Chang, Edwin Morley-Fletcher, Ludovica Durst, and Fotis Karayannis, sending an email (achang@choc.org, emf@lynkeus.com, yannis@athena-innovation.gr, l.durst@lynkeus.com, fkara@imis.athena-innovation.gr) **by March 27th, 2017**.

2. BoF on Health Data and Blockchain (Fri 7 April h 9-10.30)
Making use of Blockchain in dealing with Health Data

- Public and private initiatives, both in Europe and in the US, are currently addressing the potential of applying the blockchain approach to health data. This is related to great general expectations ("what Internet did to transaction costs regarding information, blockchain can do regarding trust") and to the assumption that what is needed for health data is a Distributed Empowerment system, providing secure access from anywhere on any device and having the Blockchain ledger as secure, non-editable record, where all transactions are confirmed by the network as entries forming blocks of transactions, and the whole network monitors the legitimacy of each transaction, guaranteeing distributed control.

- The blockchain is expected to be based on portfolios of Smart Contracts, which are the executable pieces of code, stored on the blockchain for future execution. These bind people and transactions to specific actions and outcomes and require no further direct human involvement after the smart contract has been made a part of the distributed ledger (which is what makes these contracts "smart" or autonomous).

- Can this approach be informed and controlled by the principles of lawfulness, fairness, transparency, purpose and storage limitation, data minimization, accuracy, security, accountability, as requested for instance by most data protection regulations? Can it satisfy data subjects' requests such as the right to modify, erase, be forgotten, donate data, withdraw consent, etc.?

- The HD-IG is sponsoring the idea of establishing a WG focusing on Blockchain in health data with the aim of debating in depth the potential of such a system and whether the blockchain can ensure compliance with advanced data protection requirements (such as those defined, for instance, by the EU General Data Protection Regulation – GDPR), yet making it happen seamlessly and efficiently, at scale.

- Due to its scope, this preliminary BoF meeting ideally fosters relations to a number of RDA WGs and IGs that may be able to contribute with their results to, or benefit from, the proposed future WG's activities.

The objectives of the meeting are:

- Presentation, discussion and finalization of the objectives of the case statement

- Identification of additional partners

Meeting agenda

1. Presentation of the idea behind this BoF (**Yannis Ioannidis***, President and General Director of the ATHENA Research and Innovation Center; **Edwin Morley-Fletcher**, President of Lynkeus; **David Manset**, CEO gnúbila and Head of R&I Almerys; **Aggelos Kiayias*,** chair in Cyber Security and Privacy at the University of Edinburgh and Associate Professor of Cryptography and Security at the Department of Informatics and Telecommunications, University of Athens) [40 minutes]

2. Specification of the objectives of the WG (discussion, all participants) [30 minutes]

3. Identification of other potential group members (all participants) [10 minutes]

4. Summary of the results, actions, and identification of contributions of the group members (Yannis Ioannidis, Edwin Morley-Fletcher) [10 minutes]

* To be confirmed

3. **Joint IG Big Data and IG Health Data** (Thur 6 April h 11.30-13.00) reference person Morris Riedel
Exploration Meeting

Meeting objectives

1. A key problem in exchanging big brain data tackled in big data IG is about security and privacy concerns that shall be discussed with approaches discussed within the Big Health IG.

2. Many national activities like the Smart Data Innovation Lab (SDIL) in Germany have serious limitations since big health data sharing is hindered by privacy and security concerns especially in the area of personalized medicine. Both topics are discussed in the Health Data IG. One of the Big Data IG chairs is involved in SDIL in the data innovation community (DIC) personalized medicine (e.g. https://www.sdil.de/en/communities/medicine) where approaches have been contributed to the Big Data IG but where it make sense to discuss also solutions and practices beyond personalized medicine as well as privacy and security topics for making data available.

Meeting agenda

1. Short overview of Health Data IG

2. Short overview of Big Data IG

3. Use Case: Big Brain Data Analytics within SDIL and beyond

4. Solutions and Practices for Security and Privacy in Personalized Medicine

5. Short statements from audience concerning lessons learned and valuable adopted practices

6. Discussion to find a key focus in order to potentially kick-start a WG for a specific demand derived from use case and supported by privacy/security approaches in various projects and contribution by participants.

7. Next Steps