Science Europe

Brief overview
Science Europe

- Founded in October 2011
- 52 member organisations from 27 countries
- Research funding and research performing organisations
- Represent approximately €30 billion per annum
- Policy organisation – no funding schemes

Foster excellence in EU research and strengthen European Research Area
Science Europe Structure

**Working Groups (MOs)**
- Cross-border Collaboration
- Open Access to Publications
- Research Data
- Horizon 2020
- Research Integrity
- Research Infrastructures
- Research Careers
- *Ex-post* Evaluation
- Gender and Diversity

**Scientific Committees (In)**
- Medical Sciences
- Life, Environmental and Geo-sciences
- Humanities
- Social Sciences
- Engineering Sciences
- Physical, Chemical and Mathematical Sciences

Research and management policy  Science-driven policy
The Medical Sciences Committee

2013-2014
MED Committee Members (15)

- Hakan Billig (SE) Physiology
- Stephen Holgate (UK) Immunopharmacology
- Richard Frackowiak (SW) Clinical Neuroscience
- Monique Capron (FR) Immunology
- Henrique Barros (PT) Public Health
- Martin Vingron (G) Computational Biologist
- Adam Cohen (NL) Drug Research
- Lars Fugger (UK) Clinical Immunology
- Tullio Pozzan (IT) General Pathology
- Annette Grütters-Kieslich (G) Paediatrics

Independent Scientific advisory committee
Science-driven policy
MED Committee Activities

**Strategy**

- Fostering the implementation of a health Big Data ecosystem in EU
  - Moving forward personalised medicine in EU
  - Improving ethical reviews of clinical research in EU
  - Improving science quality through implementation of the 3Rs in EU
  - Improving translational research in EU

**European regulations & Consultations**

- Data protection regulation
- Clinical trial regulation directive
- Animal use in research
- Embryonic stem cells
- Consultation “Health, demographic change and wellbeing”

**Science Europe**

- ERA consultation
- Consultation “a la carte”
MED Committee Activities

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Consultations “a la carte”
Data Protection Regulation (DPR)
## DPR: Brief Legislative overview

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<td>February 27, 2012</td>
<td>LIBE Committee Presentation of the Revised Data Protection Framework</td>
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<td>May 8, 2012</td>
<td>LIBE Committee Exchange of Views on the Revised Data Protection Framework</td>
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<td>May 29, 2012</td>
<td>LIBE Committee Stakeholder Workshop, Including EDPS and Article 29 Working Party</td>
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<td>May 30, 2012</td>
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<td>June 19-20, 2012</td>
<td>LIBE Committee Working Document</td>
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<td>October-November 2012</td>
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<td>December 7, 2012</td>
<td>Legislative deliberations of the Council of the European Union Justice and Home Affairs department</td>
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<td>January 10, 2013</td>
<td>Presentation of the amendments proposed by the rapporteur</td>
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<td>Second exchange of views on the amendments proposed by the rapporteur</td>
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<td>February 27, 2013</td>
<td>Deadline for amendments on the Draft Regulation</td>
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<td>March 2013</td>
<td>Opinions of the advisory committees</td>
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<td>Legislative deliberations of the Council of the European Union Justice and Home Affairs department</td>
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<td>April 24, 2013</td>
<td>LIBE Committee hearing on the proposed amendments</td>
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<td>May 6, 2013</td>
<td>further LIBE Committee hearing on the proposed amendments</td>
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<td>June 6, 2013</td>
<td>Meeting of EU Justice Ministers</td>
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<td>July 9, 2013</td>
<td>LIBE Committee hearing</td>
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<td>Autumn 2013</td>
<td>Informal negotiations between the European Parliament and the Council of the European Union</td>
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<td><strong>October 21, 2013</strong></td>
<td>LIBE Committee vote</td>
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<td>December 5-6, 2013</td>
<td>Meeting of EU Justice Ministers</td>
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<td><strong>March 12</strong></td>
<td>Formal adoption of Compromise Text by European Parliament</td>
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LIBE amendments: What is critical?

LIBE’s amendments to Articles 81 and 83 would prevent the secondary use of health data in scientific research without specific consent and make the use of pseudonymised health data unworkable:

- Increase costs
- Delay research
- Introduce experimental bias

It is crucial that the balance achieved in the original European Commission proposal between promoting both privacy and research is reintroduced by providing an exemption from specific consent for research, subject to appropriate and proportionate safeguards.
DPR: What is next

- Adoption of amendments by the EU Parliament on 12 March 2014 by large majority

- The Council is yet to agree its position on the Regulation.

- Once Council have adopted their position, they can enter trilogue discussions with the Parliament and the Commission

- Uncertain timescale: discussions are expected to continue until early 2015.
MED COM means of actions

- **Communication:**
  Opinion paper, joint statements, articles
  Launch a digital campaign (end November)

- **Advocacy:**
  MEPs, research community, Patient groups
  Meeting on Dec 4 with MEP JP Albrecht
  (DFG, ESRC, Welcome Trust, CNRS…)

-> Advocate and increase awareness through joint efforts with other EU organisations
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Strategy

Science Europe

Consultations “a la carte”
Workshop:
How to transform Big Data into Better Health?

Envisioning a Health Big Data ecosystem for advancing biomedical research and improving health outcomes in Europe

Erice Nov 24-25
EU faces Big health challenges

- **Complex diseases**
  multi-factorial, multi-systemic

- **Complex health challenges**
  aging, non-communicable disorders…

- **Inefficient & unsustainable R&D model**
  high attrition rate, lengthy & costly

- **Transitioning from** "diagnose and treat" to "predict and prevent"

→ **Requires a Big science approach**
“THE VISION”
Big Data: Opportunities for Big Science

“Human Information System”

Integrating multi-dimensional & heterogeneous health-related data

- Exposome
- Social network
- Clinical phenotypes
- Microbiome
- Epigenome
- Metabolome
- Proteome
- Genome
- Other type of data
- Individual subjects
The conceptual framework
From Big Data to Big Science: Creating a Health Big Data Ecosystem

- Data Integration
- Data Interpretation
- Knowledge Network
- Information Commons
- Exposome
- Signs and Symptoms
- Genome
- Epigenome
- Microbiome
- Other Types of Patient Data
- Individual Patients

- Funding models
- Infrastructure
- Expertise
- Organisational model

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Example: current organisational model

Traditional biomedical R&D value chain: linear & in silos organisational model
Stakeholders
Infrastructure
Funding
The workshop goals

1. Increase awareness of the promise and challenges that Big Data holds in transforming EU biomedical research at all stages of the value chain from understanding fundamental biological mechanisms to healthcare delivery;

2. Create a community gathering key decision-makers and performers across biomedical, healthcare and ICT research fields;

3. Develop a LT strategic vision for creating a EU health Big Data ecosystem
Workshop structure

- **Session 1**: opportunities, risks and challenges
- **Session 2**: develop a long-term vision of a EU Health Big Data Ecosystem
Thank you

Nathalie Kayadjanian PhD