

# The Medical Sciences Committee of Science Europe

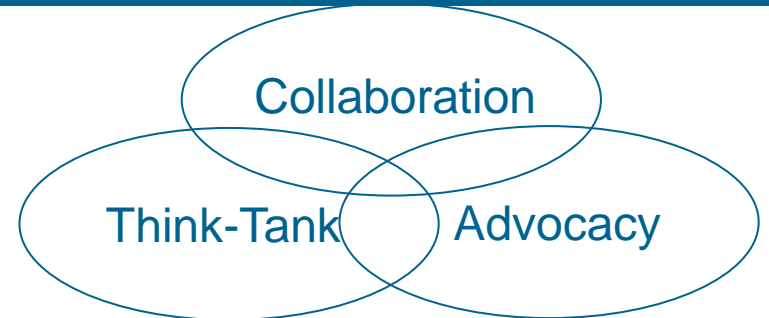


Nathalie Kayadjanian, Ph.D.

# 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

# The Medical Sciences Committee

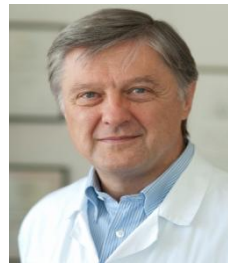
2013-2014

# MED Committee Members (15)

Hakan Billig (SE)  
Physiology



Stephen Holgate (UK) Richard Frackowiak (SW)  
Immunopharmacology Clinical Neuroscience



Monique Capron (FR)Henrique Barros (PT)  
Immunology 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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# Data Protection Regulation (DPR)

# DPR: Brief Legislative overview

<b>January 25, 2012</b>	<b>European Commission Releases Proposed Revised Data Protection Framework</b>
February 27, 2012	LIBE Committee Presentation of the Revised Data Protection Framework
May 8, 2012	LIBE Committee Exchange of Views on the Revised Data Protection Framework
May 29, 2012	LIBE Committee Stakeholder Workshop, Including EDPS and Article 29 Working Party
May 30, 2012	LIBE Committee Exchange of Views
June 19-20, 2012	LIBE Committee Working Document
July 9-10, 2012	LIBE Committee Presentation of Working Document 1
sep/12	LIBE Committee Exchange of Views
October 2012	LIBE Committee Presentation of Working Document 2
October-November 2012	Hearing
December 7, 2012	Legislative deliberations of the Council of the European Union Justice and Home Affairs department
January 10, 2013	Presentation of the amendments proposed by the rapporteur
January 21, 2013	Second exchange of views on the amendments proposed by the rapporteur
February 27, 2013	Deadline for amendments on the Draft Regulation
March 2013	Opinions of the advisory committees
March 8, 2012	Legislative deliberations of the Council of the European Union Justice and Home Affairs department
April 24, 2013	LIBE Committee hearing on the proposed amendments
May 6, 2013	further LIBE Committee hearing on the proposed amendments
June 6, 2013	Meeting of EU Justice Ministers
July 3-4, 2013	Council of the European Union Justice and Home Affairs Working Group on Information Exchange and Data Protection (DAPIX) hearing
July 9, 2013	LIBE Committee hearing
July 22-23, 2013	Council of the European Union Justice and Home Affairs Working Group on Information Exchange and Data Protection (DAPIX) hearing
Autumn 2013	Informal negotiations between the European Parliament and the Council of the European Union
<b>October 21, 2013</b>	<b>LIBE Committee vote</b>
December 5-6, 2013	Meeting of EU Justice Ministers
<b>March 12</b>	<b>Formal adoption of Compromise Text by European Parliament</b>

# 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, Wellcome Trust, CNRS...)

➔ Advocate and increase awareness through joint efforts with other EU organisations

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**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**”

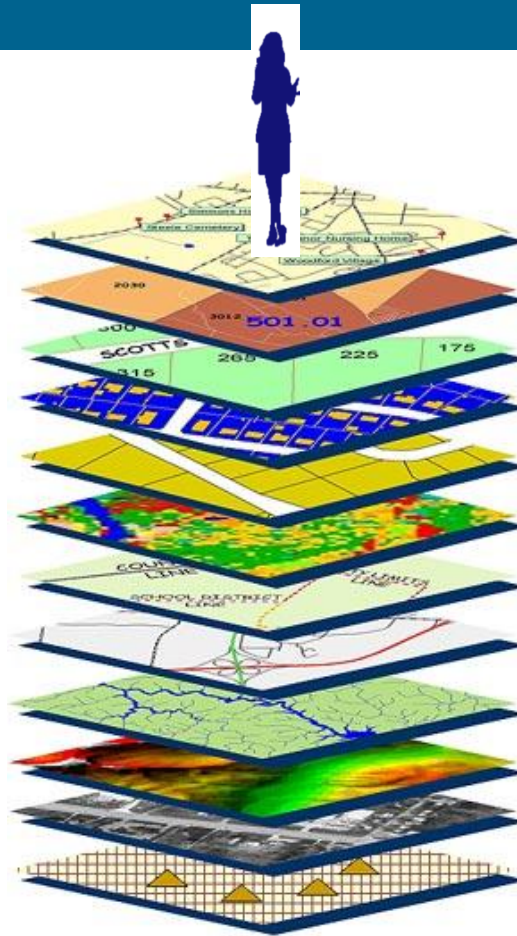
➔ Requires a Big science approach



# “THE VISION”

# Big Data: Opportunities for Big Science

“Human Information System”

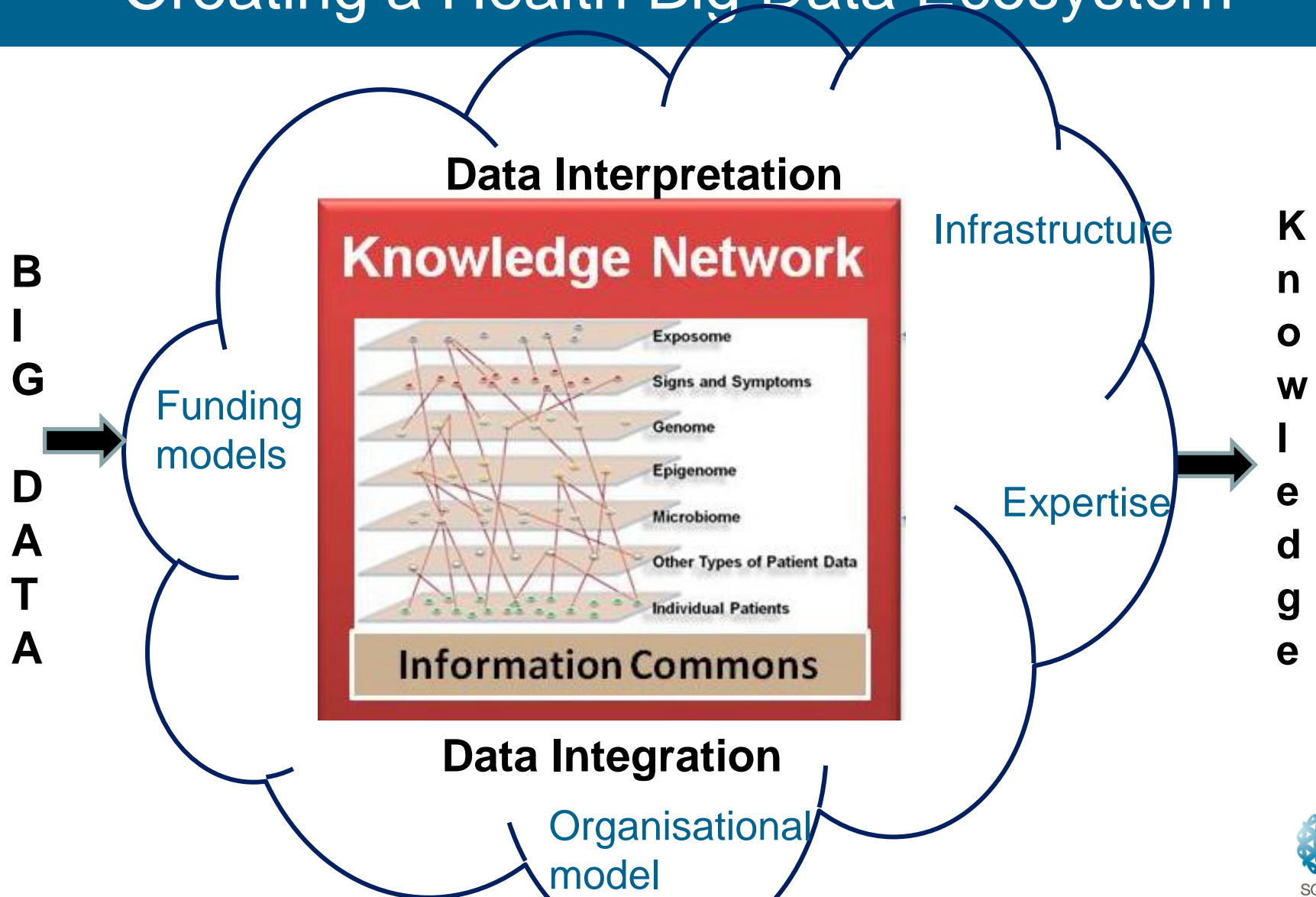


- Exposome
- Social network
- Clinical phenotypes
- Microbiome
- Epigenome
- Metabolome
- Proteome
- Genome
- Other type of data
- Individual subjects

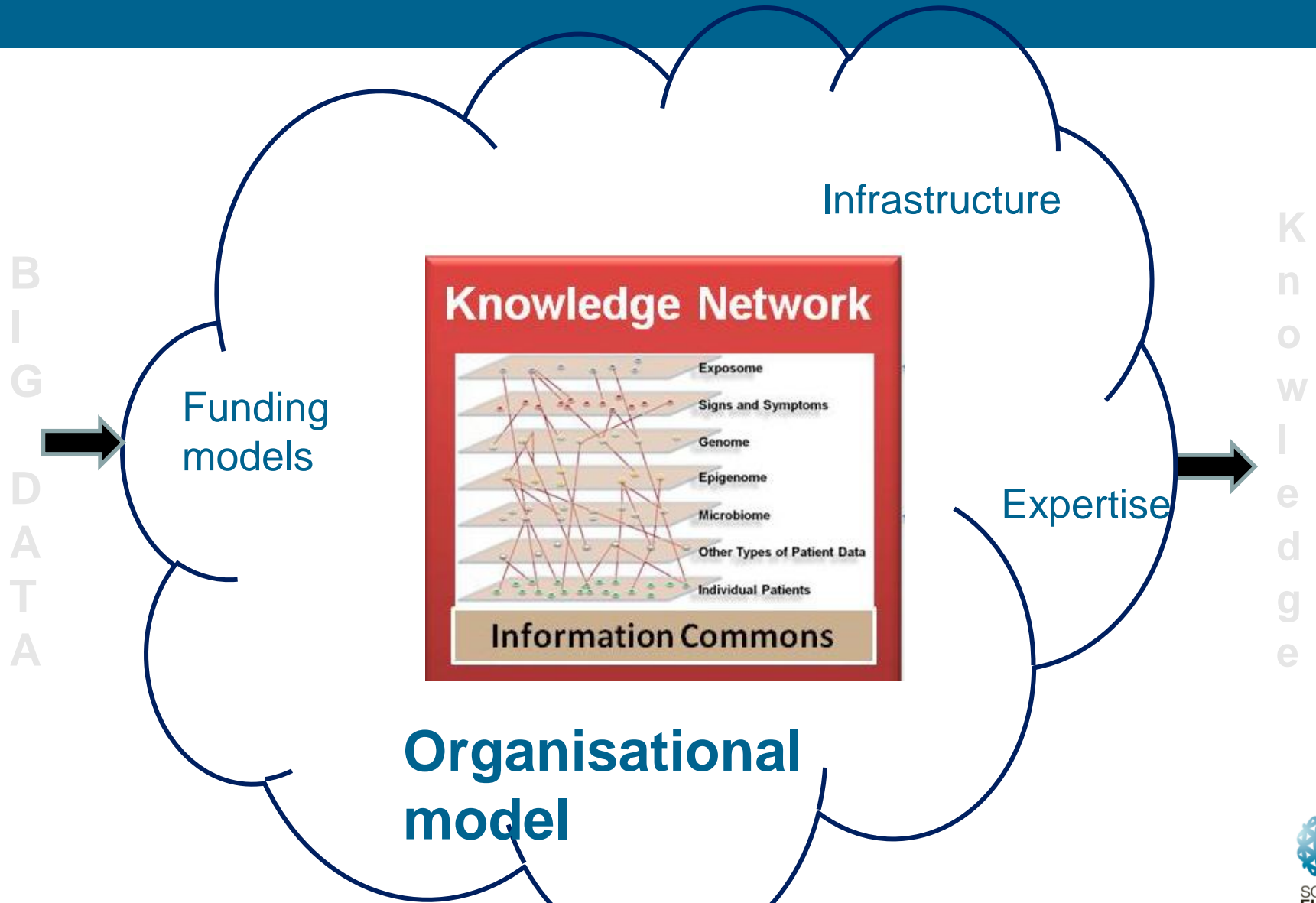
**➔ Integrating multi-dimensional & heterogeneous health-related data**

# The conceptual framework

# From Big Data to Big Science: Creating a Health Big Data Ecosystem



# Ecosystem



# 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