



BBMRI-ERIC

Biobanking and
BioMolecular resources
Research Infrastructure

BBMRI-ERIC and why we need a Code of Conduct

Professor Jan-Eric Litton
Director General
20 March 2017, Valetta

General Data Protection Regulation

Health research is not specifically addressed

nature

International weekly journal of science

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Volume 541

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Column: World View

Article

NATURE | COLUMN: WORLD VIEW



BBMRI-ERIC

We must urgently clarify data-sharing rules

Scientists have worked hard to ensure that Europe's new data laws do not harm science, but one last push is needed, says **Jan-Eric Litton**.

24 January 2017

The Road to Health & Life Science GDPR Code of Conduct

Our main concerns includes

- (a) Conditions for consent
- (b) Secondary use of data
- (c) Personal data / pseudonymisation of personal data
- (d) Defining and dealing with genetic data
- (e) Data/sample transfer to 3rd countries and international organisations
- (a) Processing in the Cloud (EOSC)



Code of Conduct - Governance

Drafting Group



Reference Group



CoC Forum

Code of Conduct - Governance

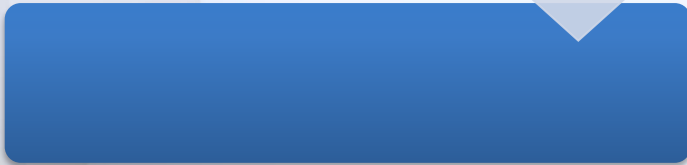
Drafting Group

- **BBMRI-ERIC (lead)**
- **ECRIN**
- **BMS RIs in CORBEL incl. EMBL**
- **EFPIA**
- **CESDA**
- **RD-Connect**

Code of Conduct - Governance



Reference Group



Rare diseases
Pathology
Cancer
Radiology
IT and e-infrastructure
Genetics
Country experts
Personal Medicine
Patient Organisations
Industry
EU Commission

Code of Conduct Timeline

February - July 2017:

Identification, alignment and outreach EU stakeholders (ongoing)

Core drafting group (April)

Identification, alignment and outreach third country institutions and international organisations

Dialogue, DPAs, Article 29 WP

Forum meeting (June)

First draft

September – November 2017:

Stakeholder consultation

Presentation Global Biobank

Week, Stockholm, Sweden

December 2017:

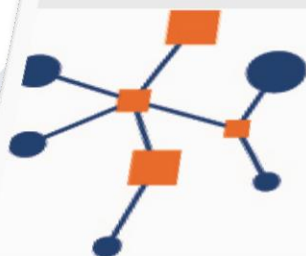
Updated draft

May 25, 2018-

Submission to Commission

Validation

Dissemination and endorsement



BBMRI-ERIC
gateway for health

Thank you!
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