



## **New Resources for Registries**

*Council of European Federations Workshop  
Paris, 15 October 2014*

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# New technology

- Electronic health records
- Open access tools
- User friendly entry points to enter and see data

# New legislation

- Data protection directive
  - Update
  - Acting today with changing requirements
  - National contact person
- Cross border healthcare directive
  - Implementation
  - Cross-Boarder Patient Registries Initiative (PARENT)

# New guidelines

- Committee of Experts for Rare Diseases Recommendation (formerly EUCERD)
- EURORDIS-NORD-CORD Joint Declaration on Registries
- U.S. Agency for Health Research Quality
- EPIRARE project
  - Website
  - Deliverables
  - Next meeting

# EPIRARE

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**Deliverables**

DELIVERABLES

> Final EPIRARE Deliverables

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**Final EPIRARE Deliverables**

[DELIVERABLE 1.1](#)  
*The current situation, the challenges and the expectations on Patient registries and Databases. I - The current context*

[DELIVERABLE 1.2](#)  
*The Current Situation, the Challenges and the Expectations on Patient Registries and Databases. II - Results of the Patient Survey*

[DELIVERABLE 1.3](#)  
*The current situation, the challenges and the expectations on Patient registries and Databases. III - Activities and needs of existing RD registries*

[DELIVERABLE 1.3](#)  
*Questionnaire*

[DELIVERABLE 1.4](#)  
*Statistical Analysis of the EPIRARE survey data*

[DELIVERABLE 1.5](#)  
*Data mining on the EPIRARE survey data*

[DELIVERABLE 2.1](#)  
*The Legal and Ethical Framework of EU Rare Disease Policies*

[DELIVERABLE 2.2](#)  
*Epidemiological and public health considerations for the EPIRARE briefing document on RD and data protection*

[DELIVERABLE 2.3](#)  
*PROPOSAL for AMENDMENTS to the Draft Personal Data Protection Legislation*

[DELIVERABLE 2.4](#)  
*BRIEFING PAPER TO THE EUROPEAN PARLIAMENT*

[DELIVERABLE 3](#)  
*Proposed Aims, Scope, Governance and Sustainability options for a European Platform for Rare Disease Registries*

[DELIVERABLE 4](#)  
*Guidelines for data sources and quality for RD Registries in Europe*

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# EPIRARE Registries Workshop



3<sup>rd</sup> International Workshop

RARE DISEASE AND ORPHAN DRUG REGISTRIES

National Center Rare Diseases  
Istituto Superiore di Sanità

c/o Casa dell'Aviatore  
Viale dell'Università, 20

November 24-25, 2014





# New public networks

- Infrastructures
  - Joint Research Centre
- Projects
  - RD CONNECT
  - EHR4CR = Electronic Health Records for Clinical Research
  - Innorare

# New companies

- OpenApp
- Patient Crossroads
- Patients Know Best



# What to do with these new resources

- Locate
- Evaluate their value to you
- Invest