

IRDiRC AUGUST 2013 UPDATE

for Executive Committee, Scientific Committees, and Working Groups



IRDiRC new documents

- Report of the third IRDiRC Interdisciplinary Scientific Committee meeting that took place in Dublin, Ireland, on April 15, 2013

Read the report [here](#)

New documents from external sources

- Two reports on Biobanks, "*Biobanks for Europe: a challenge for governance*" and "*Trust in biobank research: meaning and moral significance*"

Read the reports [here](#)

Website update

- IRDiRC is a part of Global Alliance which will develop standards and policies to enable responsible sharing of genomic and clinical data

Read IRDiRC article and The Global Alliance White Paper [here](#)

- Interview of Manuel Posada from SpainRDR which aims to build the National Rare Diseases Registry in Spain

Read the interview [here](#)

Other news

- **Planning of the past and upcoming first teleconferences of the Interdisciplinary Scientific Committee Working Groups and of the Diagnostic Scientific Committee Working Groups**

06/27/2013	Ethics and Governance (ISC)
07/08/2013	Registries and Natural History (ISC)
07/15/2013	Data sharing and Bioinformatics (ISC)
07/16/2013	Biobanks (ISC)
07/17/2013	Model Systems (DSC)
07/18/2013	Genome/Phenome (DSC)
07/30/2013	Sequencing (DSC)
08/29/2013	Ontologies and Disease Prioritization (DSC)

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