

## Report of the 1st WG “Biobanks” / “Ethics & Governance” Meeting

Dublin, Burlington Hotel

15<sup>th</sup> April 2013

### Participants

Alastair Kent, UK (Biobank WG), ISC Member

Jack Goldblatt, Australia (Ethics and Governance WG), ISC Member

Marina Mora, Istituto Neurologico Carlo Besta Fondazione IRCCS, Italy (Biobank WG)

Veronika Karcagi, National Institute, Hungary (Biobank WG)

Tsveta Schyns, EURORDIS, France (Ethics and Governance WG)

Bartha-Maria Knoppers, Canada (Ethics and Governance WG), ISC Member

### Discussions:

2 main topics were discussed:

- ▶ The urgent need for IRDiRC to inform the EU Parliament’s discussions on the need to include an exception for biomedical research as concerns the need for an explicit specific consent for every sample/data use in the proposed Directive (regulation) on data protection. IRDiRC cannot function as an international collaborative research endeavour in the absence of such exception.
- ▶ The need to organise an IRDiRC sponsored meeting on the “Governance of international data sharing”. The WG are ready to assist in the organisation of such a meeting with a focus on the development of a “Governance Framework”.

Follow-up phone calls will take place before the summer for the 2 groups separately.