Preparatory Meeting: Code of Conduct

7 June 2017, Brussels

Summary Report

The Code of Conduct needs to be able to identify and mitigate risk, to reduce opportunities for inappropriate use whilst maximising opportunities for researchers who need to have access to sensitive medical data. The BBMRI-ERIC Stakeholder Forum would be used as a sounding board to test the framework before sharing the initial draft of the Code with other stakeholder groups.

Emphasis lies on a bottom up approach and having an inclusive process, welcoming anyone who is interested to get involved. Details of all those who would like to be involved have been collected.

The possible end product and the objectives of the Code were discussed, with dialogue regarding the promotion of harmonisation across countries. Differences exist between national legislative frameworks. The Code therefore needs to have a common trunk with the possibility of opening up to allow different approaches. The end user, namely those who will use the Code to inform decision-making should be considered. The Code should provide a basis for those people who will be in institutions to make sensible and permissive decisions within the scope of the Code. It was agreed the Code should take a practical approach in order to be useful to its users, with focus on existing issues that researchers have. Patients and their families, patient groups and citizens could also be consulted to see where any red flags lie. An open line of good communication is also needed with two groups, namely ethical committees and data protection authorities.

Regular meetings are to take place on a monthly basis, with the aim of drafting the first version of the Code by Christmas 2017.

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