

## EDITORIAL

# IRDiRC-recommended

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Earlier this year, the *European Journal of Human Genetics* published a policy document by Mascalzone *et al.*<sup>1</sup> entitled 'International Charter of principles for sharing bio-specimens and data'. This Charter was recently awarded the 'IRDiRC Recommended' label by the International Rare Diseases Research Consortium (IRDiRC), which makes it a recommended guideline, recognizing its potential impact on research.

IRDiRC was set up to accelerate research and development in the field of rare diseases (including all genetic diseases), diagnostics and therapies, with objectives that most rare diseases will have a diagnostic test by 2020 and that at least 200 new therapies for these diseases will reach the market by that date. Among the initiatives identified as key to contributing to such goals is the creation of a label to highlight key resources which, if used more broadly, would accelerate the pace of discoveries and translation into clinical services. Selected platforms, tools, standards and guidelines must be of fundamental importance to the rare diseases research and development community, at a multi-national level, and which contribute directly to IRDiRC objectives.

'IRDiRC Recommended' is a quality indicator, based on a specific set of criteria. It is a public label that signals to the users of

the quality/appropriateness of a resource in contributing to the acceleration of research and development in the field of rare diseases – criteria fulfilled by the Charter, which is an enabling tool for effective and transparent data and bio-specimen sharing. When adopted by biobanks and data repositories in general, it will ensure uniformity of access across projects and countries, and will provide a consistent basic agreement for addressing data and material sharing globally. It is expected that this guideline will lead to an ethical way of sharing data and bio-specimens of relevance to advance knowledge about rare diseases. The best way to achieve this is described in this 'IRDiRC Recommended'-Charter.

Ségolène Aymé  
*Orphanet/INSERM US14, Project leader of Support IRDiRC,*  
*Paris, France*  
*E-mail: segolene.ayme@inserm.fr*

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1 Mascalzoni D, Dove ES, Rubinstein Y *et al*: International Charter of principles for sharing bio-specimens and data. *Eur J Hum Genet* 2015; **23**: 721–728.