

Task-Force on Interoperable data sharing in the framework of the operation of ERNs

Membership

Chair: KATE BUSHBY

RD-ACTION:

Ana Rath
Remy Choquet
Victoria Hedley

EURORDIS/RD-ACTION:

Yann le Cam
Valentina Bottarelli
Matt Johnson

RD-Connect:

Marco Roos
Marc Hanauer

EXPAND /VALUeHealth:

Dipak Kalra
Zoi Kolitsi

JAsEHN

Henrique Martins
Michele Thonnet
Jeremy Thorp,

PARENT-JA:

Persephone Doupi

The expertise of the TF is well-placed to address issues of data-sharing within ERN framework:

Chair Kate Bushby is a RD expert on the CEGRD and has many years of experience coordinating a network of excellence dedicated to a group of RD; furthermore, her UNEW team has robust links to the prospective leads of the future ERNs and is assembling a core group of these people. Ana Rath as Coordinator of RD-ACTION and Director of Orphanet has excellent knowledge of data-linking needs in RD, as well as the clinical and research complexities of these conditions. EURORDIS colleagues spearheaded the concept of ERNs, and advocated for their inclusion in the CBHC Directive article 12.

They were active partners in the EJA and in the current RD-ACTION and lead the PACE-ERN consortium. Zoi Kolitsi, Jeremy Thorp, Henrique Martins, Michelle Thonnet, Dipak Kalra have extensive experience in eHealth initiatives and in preparing assets for deployment in CEF. Victoria Hedley has prepared a number of policy guidance documents related to the topic of RD ERNs, has organised 3 successful workshops to support the field in realising the opportunities afforded by ERNs, and is currently leading the match-making task within WP6. RD-Connect colleagues can provide expert advice, in order that the resources of this EC-funded platform now available to link RD data for research is accessible also by Members of an ERN, to assist them in diagnosing patients and furthering research. R. Choquet and Michelle Thonnet have extensive experience of the national realities of achieving interoperability in RD data. Persephone Doupi is an expert in the field of registries and interoperability.

Observers:

From JRC: Ciarán Nicholl and Simona Martin

From DG Santé: Enrique Terol, Jaroslaw Waligora, Meta Geibel (Tapani Piha, Markus Kalliola)

From CHAFEA (Georgios Margetidis)