



RD-ACTION 'Matchmaker' for Rare Disease ERNs

Concept of the 'Matchmaker'

RD-Action is continuing the role of the previous Joint Action (EUCERD JA) to support the rare disease (RD) field in conceptualising and implementing ERNs. At the EJA Brussels [workshop](#) (1-2nd July 2015) and the subsequent meetings in Lisbon, many experts expressed a desire for a means of identifying Healthcare Providers interested in setting-up/joining an ERN in the same disease area. To facilitate discussions and collaboration between specialists, the Policy WP of RD-ACTION designed a 'matchmaker' tool. This should support collaboration and hopefully avoid duplication of efforts (and competition). The webpage explains how the process works - <http://www.rd-action.eu/european-reference-networks-erns/>

The approach is based upon the Thematic Groupings (TG) promoted by the Commission Expert Group on RD (CEGRD) in its [Addendum](#) to the 2013 EUCERD Recommendations. The process is straightforward: **anyone interested in joining an RD ERN/establishing cross-talk with others in the same Thematic Grouping should click-on one of the 21 TGs**

1. The user is directed to a Form which requests several few core details
2. Upon submission of the form, the data is transmitted to the RD-Action team at Newcastle University, UK
3. At intervals of approximately 2-3 weeks a spreadsheet of the responses received for each Thematic Grouping is emailed to all those who have submitted their data *under that same Thematic Grouping*
4. The onus is then on the specialists to use this information to make contact with one another, to continue to shape applications in each field, with the aim of encouraging collaboration and avoiding duplication

The tool was launched on 15th December and closed on 1st May 2016. It was promoted to the list of clinical and research contacts the JA has accrued, and was also disseminated by DG Sante through its ERN updates. The CEGRD was informed, along with the Board of MS. The initiative was also advertised in the OrphaNews newsletter of 19th December 2015.

Users were informed that it would be useful for the Joint Action to assess the general level of preparedness for ERNs, and to explore the status quo across the different disease areas by creating a synthesis of aggregate (anonymised) data, i.e. this document

Summary of responses to-date:

As of 30th April 2015, 801 responses had been received across the 21 Thematic Groupings. The countries in which these HCPs are based are as follows (data is reported as per the forms completed):





Country	Total no. of HCPs registering interest via Matchmaker
Europe –wide (EUROCAT)	14
Australia	2
Austria	9
Belgium	51
Bulgaria	3
Croatia	2
Cyprus	1
Czech Republic	11
Denmark	5
Finland	9
France	80
Germany	53
Greece	6
Hungary	29
Ireland	3
Israel	1
Italy	204
Latvia	1
Lithuania	20
Luxembourg	2
Malta	2
Netherlands	114
Norway	3
Poland	8
Portugal	4
Romania	3
Serbia	1
Slovenia	3
Spain	66
Sweden	15
Switzerland	8
Turkey	7
UK	61
Totals	801

Caveats for this Table:

- In some cases, **the same HCP has registered interest in several different ERNs**, so please note that, for instance, Austria’s 9 centres may not necessarily be 9 separate HCPs expressing interest
- Not all of these countries will be eligible for ERN membership, as some are outside the EU and EEA

Tailoring messages to respondents

- The UNEW RD-ACTION team supported the growing community of Matchmaker participants by alerting them to new guidance and developments; for instance,





following the launch of the Board of MS Strategic Document, [the key message that one ERN per Thematic area is expected was emphasised.](#)

- The emails accompanying some of the Excel spreadsheets are also tailored to each TG, as seemed appropriate; for instance, in the areas which have -or *seem* to have- several possible coordinators, the emphasis has been on supporting these HCPs to collaborate.
- Following discussions with RD-ACTION partner EURORDIS, the initial results of their survey of member organisations was disseminated, with the accompanying message that this list may be illuminating in terms of where patients see their diseases 'fitting' within this framework.
- In the latter mailings, following publication of the 1st Call, the team attempted to clarify the status quo within each TG by ascertaining the consensus (or lack thereof) on an overall Coordinator at this stage.

Observations from the Matchmaker

The level of interest in ERNs is very high. Although the webpage stresses that the JA cannot respond to each and every question, and has no formal role in this process, significant time and effort has been invested to support participants with their queries and facilitate the process. When completing the Forms, each HCP was asked to state whether they are: a) planning to lead an ERN application; b) already involved in an ERN application; c) not involved with an application at present but seeking to join one

The respondents were also asked to provide details of any applications they are leading or already involved with - some outlined their plans very thoroughly, which is very helpful. One observation is that often, **the HCPs selecting option a) on their Forms were in fact envisaging either i) coordinating an ERN at a much more disease-specific level than that espoused by the CEGRD headings or ii) leading a sub-group/sub-domain underneath that umbrella TG heading.** (The concept of subgroups or sub networks is integral to the success of the entire ERN enterprise.) Therefore, as the mailings progressed, the RD-ACTION team encouraged anyone who has selected option a) to share their plans with the others in their TG, which helped to distinguish between those wishing to lead a sub-group/sub domain and those intending to coordinate the ERN overall.

The UNEW team did not ask any Group of respondents whether they intend to apply under the 1st Call for ERNs (i.e. as opposed to awaiting the 2nd Call). The approach was instead to **emphasise that realistically, perhaps not all ERNs will be established at once and this will be a stepwise process.** Many Groups have shared well-developed ERN proposals by exchanging PwPs with others on their matchmaker list, to illustrate their current plans for disease coverage, disease-relevant criteria etc. Other disease areas have perhaps not networked so extensively in the past -or at least not on such a broad level as the CEGRD Groupings- but have nonetheless been very active in organising meetings and workshops to prepare for an ERN, and are reaching out to others in the field.





Key outputs and Next Steps

- A preliminary Disease mapping table was elaborated and disseminated on 23rd March. But the decisions on where to place this expertise should rest with the experts themselves.
- The Matchmaker received its last responses on 30th April 2016, to allow the Coordinators to assemble their proposals with a manageable number of HCPs (receiving expressions of interest up until the deadline for the ERN application would be impossible for them to manage)
- Through discussions with the Matchmaker communities, the team is attempting to clarify who will coordinate each ERN proposal. This is important to enable cross-talk between the coordinators.
- A table showing potential Coordinators of Potential ERNs is available here - <http://www.rd-action.eu/european-reference-networks-erns/coordination-of-rare-disease-erns/> and is frequently being updated.
- **These coordinators have been assembled into our informal 'CORE-ERN' a key stakeholder Group for the ongoing policy work of the Joint Action**

Summary of Likely Applications across the Thematic Groups

The table below shows

- the no. of Matchmaker respondents received under each TG to-date
- the number of respondents who selected option (a) '*wishing to lead this ERN*' when completing their forms initially
- an ***estimate, based solely upon the discussions via the Matchmaker**, of the likely ERN proposals being developed as of the 1st May 2016 (see <http://www.rd-action.eu/european-reference-networks-erns/coordination-of-rare-disease-erns/> for future developments)

Four key points should be emphasised here:

1. As above, **many HCPs actually intended to lead a 'subdomain' underneath the overall heading, as opposed to coordinating the ERN itself**
2. Based upon the matchmaker responses, in the majority of TGs HCPs are **combining their efforts and working towards one single ERN proposal.**
3. In a few cases, the small no. of responses via the matchmaker is *not* indicative of the overall level of preparedness and there is evidence that a proposal is developed with the requisite no. of HCPs (it is simply that few of them have completed the matchmaker to-date)
4. In a small number of cases, groups responded through the Matchmaker but declared their intention to submit a proposal for an ERN with a more narrow (though nonetheless very specialised) scope – as the Joint Action Matchmaker approach is based upon the model of the Addendum to the Recommendations on RD ERNs, information on these proposals has been included but 'linked' somehow to a Thematic Grouping in the informal table on our website.





Thematic Grouping	Total MM Responses in this TG	No. of HCPs who initially selected (a) 'wish to coordinate'	No. of ERN Proposals likely under each TG*
<i>Rare Bone</i>	19	2	1
<i>Rare Cancer/Tumours</i>	41	3	1 adult, 1 paediatric
<i>Rare Cardiac</i>	47	7	1
<i>Rare Connective Tissue & Rare Craniofacial & ENT</i>	44	4	1
<i>Rare Endocrine</i>	30	8	1 or 2
<i>Rare Eye</i>	56	6	1
<i>Rare Gastrointestinal</i>	24	4	1
<i>Rare Gynaecological and Obstetric</i>	32	4	1
<i>Rare Haematological</i>	3	0	1
<i>Rare Hepatic</i>	34	1	1
<i>Rare Hereditary Metabolic</i>	15	1	1
<i>Rare Immunological & Auto-Immune</i>	68	12	1
<i>Rare Congenital Malformations & Rare Multisystemic Vascular</i>	46	6	1
<i>Rare Neurological</i>	47	6	1
<i>Rare Neuromuscular</i>	36	7	1 or 2
<i>Rare Pulmonary</i>	48	13	2
<i>Rare Renal</i>	45	6	1
<i>Rare Skin</i>	41	8	2
<i>Rare Urogenital</i>	20	4	1
<i>Rare Skin</i>	95	15	1 or 2
<i>Rare Urogenital</i>	10	2	1
Total	801	119	





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