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Report on the sustainability of RD network tools and resources

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Keyword List:	Rare Diseases, sustainability, ERNs, eHealth, registries, ontologies	
Abstract:	An important focus of the EUCERD Joint Action WP8 ('Integration') was to support the rare disease field in preparing for future European Reference Networks (ERNs). ERNs are generally regarded as a sustainable alternative to short-term, project-funded networks. The majority of the EJA activities in this area therefore revolved around guiding the RD field towards comprehensive, robust applications following the 1st call for ERNs (i.e. conceptualising the networks *themselves* was the main goal.) However, emphasis was also placed upon exploring the sustainability of tools and resources developed by the networks, again with a focus on ERNs as opposed to smaller disease-specific network tools. Given the central importance of cross-border healthcare and research here, it was necessary to build and develop links with key eHealth initiatives and stakeholders.	
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1. Introduction

An important element of WP8 ('Integration') of the EUCERD Joint Action: Working for Rare Diseases (N° 2011 22 01) concerned the identification of actions to support the sustainability of rare disease (RD) activities and resources. The RD field is unique, comprising a large number of heterogeneous disorders, each with a small (indeed sometimes miniscule) number of patients. Expertise in any given RD tends to be scarce and often fragmented. When such small numbers of patients are afflicted by any single disease, knowledge and understanding of these (often complex) conditions is difficult to accrue, and necessitates a pooling of precious patient data across borders to enable a 'critical mass'. In short, transnational collaboration in RD is not merely desirable, it is essential – and to maximise the impact of any RD activities or initiatives, there should ideally be a plan for sustainability.

One of the four Tasks of WP8 was dedicated to 'networking the networks' – in essence, this Task entailed supporting the RD field in preparing for the advent of European Reference Networks (ERNs). Rare Diseases were declared a priority area for Community Action in the 2nd (2008-2013) Public Health Programme, in recognition of the added-value afforded by a collaborative approach, by sharing knowledge and expertise between Member States (MS) and through fostering multistakeholder interactions. Many projects were funded prior to the commencement of the EJA in May 2012, which were primarily dedicated to establishing European-wide networks in particular diseases or disease areas (e.g. Cystic Fibrosis, McArdle Disease, rare diabetes syndromes, rare anaemias, Haemophilia, intoxication-type metabolic disorders, etc.)[1] These initiatives stemmed from the recognition that increasing patient access to diagnosis, treatment and care for RD demands shared efforts in particular areas: increasing the visibility of expertise, so that patients and doctors know which healthcare centres across Europe have expertise in particular disorders or groups of diseases; gathering a critical mass of high quality data on RD patients, usually via a registry, to support epidemiology and natural history in order to increase understanding of the condition; reaching consensus on what constitutes optimal care, by defining best practice guidelines and disseminating these; supporting research and therapeutic development (particularly important in a field in which the majority of diseases have no dedicated medicinal products), etc. However, once the funding periods end it has traditionally been very difficult to sustain RD networks and the resources they have created – more permanent, sustainable infrastructures are necessary, and ideally a means of embedding expert networks in highly specialised healthcare into the national health and research systems of Europe.

The EJA Task of 'networking' these existing networks quickly evolved into a multifaceted goal of providing support to the RD field at large, to maximise the opportunities afforded by the future ERNs.

2. Presentation and analysis of results

The focus of this report is the *sustainability* of **network tools and resources**, which potentially can encompass many things - to support health and research appropriately, many tools and assets must be available and sustainable within the RD networking environment, including:

- Tools and resources to allow the virtual delivery of care within a network (e.g. eHealth tools, telemedicine platforms to allow virtual consultation of a patient or virtual clinical boards to take place)
- Registries and databases: many of the disease-specific Actions/ networks funded under the 2nd Public Health Programme prioritised the creation of a registry
- Tools to facilitate research within a networking environment (for instance registries containing genetic information, clinical trial site registries)
- An appropriate ontology with which to code RD. The OrphaCode is considered the optimum system to capture the granularity of RD and via a partnership with EBI has been expanded into the Orphanet Rare Disease Ontology (which recently received 'IRDiRC Recommended' status[2]).

2.1 Support and Capacity-Building on the topic of European Reference Networks

In order to sustain networking tools and resources, **it is necessary to seek longevity of the networks themselves**, which develop and deploy these assets. A major focus of the Integration WP was therefore to support the RD field (at various stakeholder levels) in preparing for the 1st call for ERNs, with the aim of achieving the best possible ERN applications. This was achieved by identifying and uniting networking experts into Working Groups, integrating stakeholders at key workshops (three were dedicated to ERNs across the course of the EJA), carefully analysing the legislative documents addressing ERNs, identifying gaps specific to the RD field which need to be addressed by ERNs, defining ways to fill such gaps, and generating guidance and supporting documents to encourage the RD field to conceptualise and create ERNs which add value and hold the potential to make a real impact. The major EJA activities in this respect were as follows:

- Organisation of an expert workshop to draft Recommendations on ERNs for the RD field (2012)
- Supporting the elaboration and revision of the *EUCERD Recommendations on RD ERNs* (2013)

[1] http://ec.europa.eu/chafea/projects/database.html provides a searchable database.

[2] http://www.irdirc.org/activities/irdirc-recommended/

- Conducting a comparison exercise between the EUCERD Recommendations and the formal Delegated and Implementing Acts for ERNs (2014)
- Organising a second expert workshop aimed at MS Competent National Authorities and other key stakeholders, to explore how to address the specific needs and priorities of RD through ERNs
- Conceptualising and elaborating an Addendum to the EUCERD Recommendations, in order to group RD thematically (to ensure a comprehensive, logical and equitable coverage of all diseases) and to emphasise the importance of active, meaningful patient involvement in ERNs (2015)
- Uniting RD experts from diverse clinical areas via a third workshop (2015)
- Drafting formal Frequently-Asked-Questions (FAQs) on the procedural aspects of ERNs with the European Commission (2015)
- Leading a RD workshop during the 2nd Official EC Conference on ERNs in Lisbon (2015)
- Forming plans for a 'Matchmaking' tool to support RD clinical groups in formulating comprehensive ERN proposals, to minimise duplication or competition

The EJA partners recognised that if ERNs were to be sustainable, it is essential that they are envisaged and implemented at the appropriate 'level' or scale –a solid strategic framework was necessary, with which to unite existing smaller-scale networks under a limited number of broad headings or Thematic Groupings. The EUCERD Recommendations adopted this perspective, recognising that without some attempt to group diseases into Themes,[3] it would be impossible for ERNs to provide a 'home' for all RD. Given the legal necessity for Networks to include at least 10 healthcare providers in at least 8 MS, it was acknowledged in the Acts that:

> "*It might be difficult to reach the minimum number of healthcare providers or Member States for some rare diseases or conditions due to a lack of expertise. It would therefore be a good idea to group healthcare providers that focus on related rare diseases or conditions in a thematic Network*".[4]

For this reason, and in view of the need for greater clarity on the role to be played by patients and their representatives, the concept of an Addendum to the original 2013 Recommendations emerged, and became a major focus for WP8 and for partner EURORDIS. The Addendum suggested an illustrative grouping of RD as a feasible approach to RD ERN planning and to ensure coverage of all RD eventually.

[3] "Based around the concept of medical specialties and body systems, diagnostic and therapeutic areas can be identified each covering a wide range of rare diseases. Comparison of the systems in place in MS with well-developed services for rare diseases shows that the number of diagnostic and systemic areas which might cover the majority of diagnoses could be approximately 20-30." (Recommendation 19)

[4] Preface to the Commission Implementing Decision (6)

The fact that there are 6,000 - 8,000 separate RD necessitates a comprehensive, overarching framework to avoid establishing potentially hundreds or even thousands of individual networks and ensure that a reasonable number of well-integrated RD ERNs have adequate capacity to address all of these conditions. The EJA led a piece of work exploring possible models of grouping RD by area.[5] This was reviewed and revised at various workshops and at meetings of the Commission Expert Group on Rare Diseases (CEGRD) which adopted the Addendum in May 2015. The Groupings eventually recommended by the CEGRD were as follows:

Rare immunological and auto-inflammatory diseases
Rare bone diseases
Rare cancers* and tumours
Rare cardiac diseases
Rare connective tissue and musculoskeletal diseases
Rare malformations and developmental anomalies and rare intellectual disabilities
Rare endocrine diseases
Rare eye diseases
Rare gastrointestinal diseases
Rare gynaecological and obstetric diseases
Rare haematological diseases
Rare craniofacial anomalies and ENT (ear, nose and throat) disorders
Rare hepatic diseases
Rare hereditary metabolic disorders
Rare multi-systemic vascular diseases
Rare neurological diseases
Rare neuromuscular diseases
Rare pulmonary diseases
Rare renal diseases
Rare skin disorders
Rare urogenital diseases

The WP8 team provided support to the clinical RD communities in terms of understanding the meaning of this list of Disease groupings and how it could be used. The primary goal of the proposed scheme is inclusivity at the European level – it is important to emphasise that member healthcare providers/CEs will *not* need to be designated (or re-designated) to align precisely with one of the 21 Themes. In all likelihood, the members of any given ERN will not possess the same level of expertise for all the RDs within that ERN; however, organising

[5] See forthcoming: Evangelista, T et.al. (2016) 'The context for the thematic grouping of rare diseases to facilitate the establishment of European Reference Networks' *OJRD*

ERNs at the level hereby proposed will help to close the gaps. Although RD are often multisystemic disorders, they can *usually* readily be classified under these headings; the medical expertise necessary for multi-system care will largely be provided -as at present- by CEs involving experts from various disciplines. The success of this framework will be ensured by effective cross-links between the different RD ERNs.

Presentations on the Addendum and future needs of ERN communities led increasingly to the EJA Coordination team receiving requests for informal advice on how best to use the existing RD policy and guidance documents to establish robust ERNs. Similar queries and misconceptions were often encountered, leading to the generation and approval of a set of formal Frequently-Asked-Questions[6] in partnership with DG Sante. Towards the end of the EJA, it was decided that a less formal set of FAQs would also be very helpful for the field, particularly for those not so closely involved to-date in the ERN topic.[7] Also planned under the EJA but implemented by RD-ACTION WP6 was a 'match-making' tool to assist Healthcare Providers in identifying and collaborating with others interested in an ERN under the same Thematic Grouping.

2.2 Network Tools and Resources - Registries and Databases

Registries are essential tools in RD networking. In recognition of the diversity and lack of interoperability in RD registration across Europe, the EJA organised working groups and expert workshops in order to prepare a set of *Recommendations on Rare Disease Registration and Data-Sharing*, for consideration and eventual adoption by the EUCERD. Under the Registries task, two additional outputs were generated by WP8 (specifically by the team at GUF led by Thomas Wagner): a *Minimal Data Set for Rare Diseases Registries (January 2015)* and a *Thesaurus of Registry Terminology (January 2015).*

Over the course of the project, an unexpected development occurred which had far-reaching implications for the sustainability of RD registries. The Institute for Health and Consumer Protection (IHCP) at the Joint Research Centre (JRC) in Ispra signed an administrative agreement to implement a European platform for RD registration. This platform would theoretically be a permanent structure. The WP8 outputs were disseminated to the JRC team, for consideration, and informed the development of the OSSE system in Germany[8]. Each of these hold potential to harmonise RD registration efforts in Europe; however, following their creation, there were limited opportunities to explore how these might gain consensus in the RD field and be used to stimulate the creation of registries collecting similar data items for similar purposes (four distinct registry

[6] http://ec.europa.eu/health/ern/implementation/faq_en.htm#aa

[7] Post-script: this was completed under RD-ACTION and is available here: http://www.rd-action.eu/wp-content/uploads/2015/12/Informal-FAQs-and-Discussions-on-RD-ERNs-Jan-2016.pdf

[8] https://www.unimedizin-mainz.de/imbei/informatik/ag-verbundforschung/osse.html

'modules' were envisaged in the EJA Minimum Data-Set: basic registries, clinical registries, research registries and post-marketing surveillance registries).

At the end of the EJA the precise scope and services offered by the JRC platform remain to be clarified. Several policy scenarios[9] had been proposed for this platform:

1. Support for new registries (e.g. creating/hosting guidance documents, providing sample consent forms etc.)
2. Promotion of the interoperability of existing standalone registries (e.g. by developing/promoting interoperability standards)
3. Act as a hub providing access to all data collection in the field of RD
4. Provide IT tools to maintain already existing data collection

Scenario 3, particularly, would potentially be a major undertaking, depending upon the scope of such data collection. For instance, would the JRC platform serve as a repository for data for ultra-rare diseases with no existing registries? Would core datasets (whether common to all registries and/or disease specific) in use by existing registries be uploaded to the JRC platform? Without greater understanding of the role of this platform, it is difficult to predict any sustainability consequences for individual registries, including those used at present in networking environments.

The vision espoused by the *EUCERD Recommendations on RD ERNs* is that ERNs should share tools such as registries; however, precisely *how* ERNs will actually use registries/interact with registries is by no means clear. One option would be to envisage a new registry specifically created for each ERN. This would be a major undertaking, and would require dedicated funding, to be sustainable. Another option would be to integrate and expand existing disease registries for use by each ERN as a whole; however, if ERNs are established with the level of disease coverage anticipated in the Addendum, no existing registries would be able to address the full scope of conditions under each heading, for instance *all* rare haematological diseases (although there are some which cover a sub-set of haematological diseases).

At the end of the EJA, it is expected that the four workshops to be organised by the JRC in 2016 will enable further debate as to how registries and databases will be used by ERNs, and will elucidate the realistic opportunities for sustainability via the JRC Platform.

2.3 Sustainability of RD-appropriate ontologies

Ontologies should be considered an essential tool to support networking in the RD field, on the basis that the use of appropriate ontologies is necessary to ensure the cross-border interoperability of data. RD are typically far less 'visible' in health information systems in comparison to more common diseases, as the major systems of disease classification are at present unable to capture the complexities and granularity of RD. (e.g. ICD 10 can only code ca. 250 of 8000 RD). Promoting use of a shared -and RD appropriate- coding nomenclature is thus a key priority for the field. The OrphaCode/Orphanet Rare Disease Ontology (ORDO) is considered by many academic clinicians, by RD-Connect, and by IRDiRC to be the preferred means of coding rare diseases.[10]

Realistically, however, health systems as a whole will continue to focus upon the mainstream disease nosologies. For this reason, important work was conducted in the EJA to cross-reference different terminologies via Orphadata. When diseases are added to the Orphanet portal, they receive an OrphaCode, alongside which can be found an equivalent code (where existing) in ICD 10, SNOMED-CT, OMIM, UMLS, MeSH and MedDRA. EJA WP5 leader Ségolène Aymé led the Rare Diseases Topic Advisory Group (RD TAG) preparing the 11th version of the ICD-11. This work aimed to ensure an exhaustive coding of RD in future ICD versions. **The cross-referencing work, as well as the maintenance and updating of the ORDO itself, must be sustained in order to support the sharing of data between HCPs in an ERN.**

2.4. eHealth and interoperable data-sharing within the ERN framework

One of the primary aims of an ERN is to enable *expertise* to travel, as opposed to patients, when appropriate. This essentially means that the healthcare services provided by an ERN (as opposed to their component member Healthcare Providers (HCPs)) will be largely **virtual** services. Virtual healthcare or eHealth services can entail various scenarios. For instance, one might envisage a patient participating in a teleconsultation attended by several experts. Alternatively, a virtual meeting of experts might be arranged, at which complex patient cases are discussed and images, scans, x-rays etc. are uploaded to a shared platform in order to assist in determining a diagnosis/the most appropriate treatment regime etc. In the rare cancer field, such 'virtual tumour boards' are held regularly, in real-time; however, another option would be to upload the same patient data for analysis by geographically-distant colleagues individually, at different times, using a collaborative application which enables the posting of comments or reports.

Existing RD networks (often research-focused) have, in some cases, developed bespoke eHealth systems or purchased ICT platforms to enable this kind of virtual networking 'shared-care'. Their partners based in

[9] http://www.eucerd.eu/wp-content/uploads/2013/06/WP8WorkshopEJAEPIRARE.pdf

[10] http://ec.europa.eu/health/rare_diseases/docs/recommendation_coding_cegrd_en.pdf

centres of expertise across Europe, sometimes globally, are able to exchange knowledge and expertise in precisely these sorts of ways, which is more appropriate and effective than less formal means of seeking second opinions from colleagues outside their own health jurisdictions. It was never a Task of the EJA to explore such specific tools or assets – eHealth as a concept was in fact largely absent from the initial proposal. However, as the Coordinators recognised that eHealth would be central to the success of the ERNs, given that all the core activities of an ERN will involve data sharing, collaborations were formed with key experts from the eHealth field. Synergies were built particularly with projects involved in the cross-border exchange of data for health, such as EXPAND/epSOS, eSENS, Joint Action to Support the eHealth Network (JASeHN), SemanticHealthNet, EHR4CR, etc., with the goal of linking the work of the RD and eHealth communities to ensure that ERNs will indeed function effectively as infrastructures to provide cross-border healthcare in disease domains where expertise is scarce and fragmented.

In its final year, EJA WP8 began to explore concrete activities and use cases with which to leverage the expertise of colleagues in the eHealth field -concentrated around unplanned/emergency care received on a cross-border basis- and apply this to the ERN environment. Although the core roles and duties of ERNs are relatively clear (being defined in the Delegated and Implementing Acts), the tools and resources which will be available to ERNs to allow them to carry out these duties are not yet evident. It is acknowledged that appropriate ICT platforms will be necessary to allow the exchange of patient data, and these would be provided for each of the networks by the EC.

In launching these preliminary activities, EJA WP8 adopted the position that ERNs will need to do more than simply share patient data on an individual basis for direct care. It is clear that ERNs will be expected in time to be able to share patients' data (diagnostic information, clinical symptoms, MRI scans, tumor images etc.), as above, between HCPs in different MS - this much appears certain. However, if this is the ultimate extent of the data sharing (i.e. on an individual case-by-case basis) then the field will have missed a major opportunity to collect, store and share aggregate data for 'secondary' purposes. Such data is highly relevant to 'care', as re-use in this way increases knowledge and understanding of RD (e.g. epidemiologically) and translate into improvements to healthcare. It also supports research, which is the main route to providing more numerous - and higher quality- therapeutic options for patients, especially important in the RD field where the majority of diseases have no dedicated treatments. The opportunity afforded by designing and building a formal network consisting of a (relatively) small number of expert HCPs –the minimum is at least 10 providers in at least 8 MS- active in the same broad RD Grouping must not be underestimated. For example, given the desirability of interoperable, comparable data, the prospect of each HCP collecting specific shared data elements on the patients they encounter (either 'encounter' within the ERN consultation sphere, or else 'encounter' as a HCP generally) and sharing elements of this information safely and interoperably (meaning at all levels of interoperability) holds great potential.

2.5 Sustainability of eHealth tools and resources in the ERN framework

Adding to the uncertainty surrounding the exact eHealth tools to be provided to ERNs, there are questions concerning the sustainability of these platforms. Towards the end of the EJA the European Commission (DG Sante) allocated funding to support the IT platform for ERNs under the CEF (Connecting Europe Facility).

The CEF was set-up in 2013 and is funded until 2020, to determine the conditions and methods for providing EU financial assistance to trans-European networks in three sectors: transport; energy; telecommunications. The latter is divided into 'broadband' and Digital Service Infrastructures (DSI). Under the DSIs, CEF finances:

- "building blocks" - assets which are reusable by specific projects;
- "Core Service Platforms" which provide centrally-operated (i.e. EU) cross-European solutions.
- "Generic Services", i.e. services which are designed to link national infrastructures with the Core Service Platforms.

The final CEF workplan of 2015 confirmed that, for the first time, two types of e**Health** DSIs will be funded - http://ec.europa.eu/digital-agenda/en/connecting-europe-facility – especially pages 35-40. The Generic Services relate to the ePatient Summary and ePrescription, delivered by epSOS and eSENS. A solid technical and organizational infrastructure will be established and extended, deployed in around 12-15 countries (realistically those involved in epSOS and eSens, which are able to deploy these DSIs now). The Core Service Platform funding has been allocated to develop the ERN IT platform.

The incorporation of ERN-related DSIs into the 2015 CEF workplan was made possible by the eHealth Network's identification of ERNs and Registries as eHealth priorities (alongside the ePatient summary and the ePrescription). Therefore, the CEF -or rather the funding available through the CEF- is a possible avenue of sustainability for RD networking tools and resources. In view of this, and to maximise the potential for ERNs to benefit from CEF support, the EJA formalised its collaborations with several eHealth projects, by developing an Exploratory Paper on the *Convergence of Rare Disease and eHealth initiatives* (Annex 7). At the end of the EJA, a Task Force was established on 'Interoperable data sharing within the framework of the operation of RD ERNs' by the EJA/RD-ACTION. Under RD-ACTION this work will evolve and take shape, with the expectation to agree a limited number of **concrete activities or use cases** in which the knowledge and experiences of the eHealth field can be leveraged by the RD community, to optimise the sharing of data for care and research in the ERN environment. There may be potential to deploy assets under CEF 2016-2020. Such activities will be conducted with due caution, however, in acknowledgment of the fact that CEF is only operational until 2020. After this point, it is possible that an alternative means of funding the ICT platforms and eHealth assets will need to be found. For this reason, the EJA/RD-ACTION is actively involved in the H2020 project "VALUEeHealth" which is seeking a sustainable business model for CEF-funded eHealth infrastructure.

3. Conclusion

Concerning the sustainability of RD network tools and resources, the most important contribution of the EJA has been to support the field in preparing for the first ERNs. The Networks themselves, once established, will not be time-bound and will therefore avoid the sustainability challenges faced by networks resulting from EC project funding: they will, presumably, be permanent structures. The sustainability of the tools and resources they will **share**, however, is less clear.

How ERNs will use/engage with registries and with the JRC platform remains to be determined. What *is* clear is that registries play a vital role in pooling data for numerous purposes, which are very much in line with the mandate of ERNs: enabling a critical mass of data to be gathered for epidemiology; assessing the relative efficacy of therapeutic products; defining best practice guidelines; assessing the feasibility of research studies; recruiting patients for clinical trials; supporting the planning of health services, etc. The sustainability of these tools is linked to the way in which they are ultimately developed or incorporated into the ERN framework – and this framework will be very different to any existing networks which have created and maintained registries hitherto.

The **Task-Force on Interoperable data-sharing within the framework of the operation of ERNs**, established at the end of the EJA, should play an important role by attempting to ensure that data entering the ERN framework is shared, stored and reused optimally, to enable ERNs to fulfil their expectations for all RD stakeholders. This means embedding *RD-appropriate* tools in whichever IT platform is provided for the ERNs. It also entails capturing and storing data in such a way as to enable essential linkages with existing pan-European research infrastructures funded by the European Commission and the Member States, such as the RD-Connect platform[11] and the ESFRI infrastructures (perhaps ECRIN, ELIXIR, BBMRI and EATRIS in particular[12]). By analysing existing networking tools and resources in greater detail, from an eHealth and interoperability perspective, the Task Force will foreseeably identify and promote good practices for sharing data within ERNs. Simultaneously, the focus upon CEF funding and, crucially, the post-CEF period, will enhance the prospects of equipping the future ERNs with optimal and sustainable tools.

[11] http://rd-connect.eu/

[12] http://ec.europa.eu/research/infrastructures/index_en.cfm?pg=what

4. List of Annexes

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Annex 3: Comparison between the *EUCERD Recommendations on Rare Disease ERNs* and the Delegated and Implementing Acts for RD ERNs

Annex 4: Preparatory Discussion Document to outline the 'Specific Criteria and Conditions' in the field of Rare Diseases

Annex 5: Report: Conclusions and Action Points from EJA Workshop on RD ERNs and Structural Funds

Annex 6: Addendum to the EUCERD Recommendations on RD ERNs

Annex 7: Exploratory paper – Convergence of Rare Disease and eHealth initiatives