

ERNs and the status quo of integrated care for rare and complex diseases

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ERNs '101'



ERNs must possess/must demonstrate

- ✓ knowledge and **expertise to diagnose, follow up and manage patients**
- ✓ Evidence of **good outcomes**
- ✓ **multi-disciplinary** approach
- ✓ capacity to **produce good practice guidelines and to implement outcome measures and quality control**
- ✓ collaborate with **other CEs and networks**
- ✓ **Research, teaching and training**

Integrated, Holistic Care: Where might ERNs come in?

- Why are we here?
- RD-ACTION Guiding Mantra 😊 - As ERNs are established & evolve, dedicated guidance is important to support and also to ensure a baseline compatibility and interoperability (at many levels) between the ERNs
- Opened an invitation to one representative from each ERN, and invited ePAG applications
- Note – these workshops are a ‘first look’ at these issues
- Always have some case studies – not possible to showcase all, therefore to give each a ‘voice’:

Survey Responses

- 15 complete responses from 14 ERNs
- We will probably re-open the survey at a later date, to get more comprehensive coverage (and see how people's attitudes change 😊)
- Capacity in which people completed:

Representing ERN /is Coordinator or Group leader	5
Personal capacity representing an HCP	5
ePAG	3
Both ePAG and personal capacity	2

Definitions!

- What people mean by IC and holistic care (and the two are quite different though complimentary) is crucial here:
- Note focus on Legal Acts for ERNs is 'healthcare' often
- Please note that 'Integrated Care' is defined in this context as follows: Integrated care pathways are based on a person-centred, multidisciplinary, holistic, continuous and participative care provision. They enable the exchange of information and the coordination between health, social and other support services located at national, regional and local levels. Integrated care pathways are expected to improve the quality of life of patients and their carers, while also reducing their care burden. Integrated care is expected to increase the quality of care and lead to efficiency gains in care provision.

1. Relevance of the Topic to your ERN

- 1.a) How highly do you (personally) value the mission of promoting an integrated, holistic approach to care for people with rare and very complex conditions (regardless of WHO is promoting it, whether it is an ERN, an HCP, an individual, or other actor)?
 - I see this as very important
 - I see this as important
 - I see this as reasonably important
 - I see this as fairly unimportant
 - I do not think this is an important mission for people with rare and very complex conditions

12 – very important
3 – important

2. Priorities...

- Q2) If resource/time were not an issue, how far do you consider it SHOULD be a goal of your ERN to improve the provision of Integrated Care for people with rare/complex diseases?

- This should be a very important goal for my ERN
- This should be an important goal for my ERN
- This should be a reasonably important goal for my ERN
- This should be a fairly UNimportant goal for my ERN
- This is not at all relevant for my ERN

10 – very important goal

1 – important goal

2 – reasonably important goal

- “Indeed important to consider whole patient pathways, to guarantee all aspects of QoL, care and cure of patients”
- “We work to improve QoL of patients and families so holistic approach necessary”
- “Unless care is integrated it is of no value to the patient”
- “Integrated and holistic approach only means to address problems pertinent to RD in comprehensive, coordinated and also cost-effective way”
- Several cited ‘Lack of treatment and curative options, combined with other issues like many organs involved (so multidisciplinary medical cited here), things like depression”
- “Important to find a general balance not just medical one, for best possible QoL”
- “Sharing loses nothing, only stands to gain”

First impressions on how ERNs/their HCPs can add value

ERNs could perhaps:

- Spread understanding of the benefits of joined-up, holistic care pathways for patients (encompassing less strictly medical professionals, such as physiotherapists, psychological therapists, and social support appropriate to the specific needs of people with rare diseases and their families)
- Support and propel the drive to identify how best to provide care for patients with rare and complex conditions and define patient pathways (e.g. ERNs may help to define best practices and support their inclusion to comprehensive clinical practice guidelines or care guidelines)
- Create personalised health and social care plans for people with rare diseases, possibly both those receiving virtual referrals and the patients visiting constituent HCP
- Engage in tertiary prevention activities, including the creation of dedicated guidance from the ERN for patients and families and for local health and social actors (some activities may of course sit more logically with the actual Centres of Expertise i.e. the HCPs here)
- Embed good practices to support integrated care for patients in their constituent HCPs (and eventually 'affiliated' partners), and in time help to diffuse good practices to broader health systems
- Contribute to the collection and integration of data, to improve knowledge and understanding of rare diseases and the impact of patients and wider society

Q3 – Comments on initial ideas

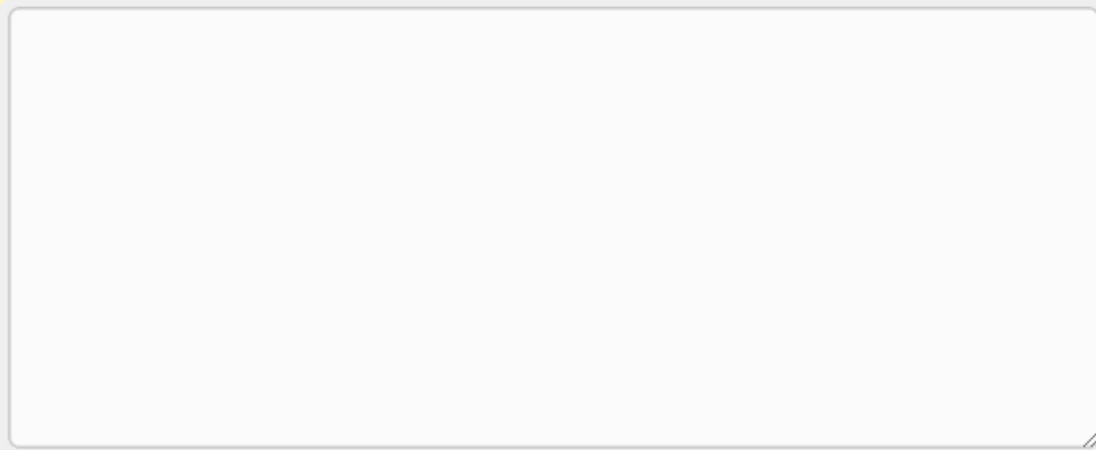
- Generally positive, helped us think of tangible things (we will return to them!)
- ‘ERNs (their HCPs?) could be like national reference centres to inform other HCPs about resources in RD/complex procedures”
- Fighting stigma of conditions (Epilepsy) and looking for social and sports integration
- “Min. could be promoting IC, working for patient empowerment, making healthcare professionals and non-healthcare professionals aware of RD patient needs”
- “Possible role in Establishment of BPGs for IC/holistic care; research into socio-economic aspects of I/H Care”
- “My ERN wants to create personalised health and social care plans”
- “ERNs could provide guidelines for those diagnosed”
- “ERN itself cannot deliver this sort of care – in the end it is the patient’s healthcare actors who regularly follow that person. ERN can establish guidelines and consensus on how certain situations should be managed. ERNs should educate professionals and authorities on benefits of holistic care.”

Q4 – Looking for good practices and inspirations

- **4. Are you aware of examples of any pilots/projects/grants - ongoing or completed- which specifically focus on the provision of Integrated or Holistic care for any disease/group of complex conditions under the overall scope of your ERN?**
- Few examples here, however:
 - PaedCan ERN highlighted the Standards of Care generated in 2013, Survivorship Passport
 - TAG project – improving health and social care support for people with rare skin disorders. Plus Genodermatoses and rare skin disorders Network launched 2003 highlighted

Current ERN plans?

5. Has your ERN yet taken any steps/made any plans to address/improve the provision of Integrated and holistic care to patients in Europe living with any of the conditions under your ERN's scope? *



E.g. is there a plan to generate personalised care plans for patients referred to the ERN for shared care/patients seen by the HCPs?

Are there any plans from the ERN to generate advice/ to support patients in receiving a particular 'combination' or standard of care in the wider community (e.g. in the domains of specialised counselling, therapy, social care, recreational, education, etc?)

Again, few concrete plans at this stage

- General view that more time needed!
- “Patient/family participation being promoted to detect common problems facing children in transplant process and how HCP current resources can improve QoL”
- “A WG e.g. for low vision and patient care/involvement which should cover holistic approach to rare eye”
- Paediatric cancer continuing close working with parents and patient orgs, e.g, survivorship passports

Cont.

- “ERN-Skin developing an individual skin burden score, which takes into account health related QoL, social integration, home-life, use of medical and non medical resources. Has also conducted survey on patient education programmes available at HCP level and plans to develop tailored programmes for children, teens and adults. Promotes involvement of paramedical team and social worker in care pathways”
- Interestingly, several mentioned the CPMS (Clinical Patient Management System)
- Question for the discussion – how far do people see this CPMS being used for these sorts of activities? What would need to be addressed for this?

Q6: Barriers

- **6. What do you see as the main barriers to the ERN making a positive difference in the integrated /holistic care sphere?**
- One did not see barriers which is good!
- Resources was high on list!
- ‘Lack of communication scenarios among stakeholders’
- “Diversification of services available by pathology”
- Many teams in ERN just medical doctors, no paramedical, no therapists, no way to involve educators etc’

Barriers cont.

- Different laws in different countries”
- “Differences in health systems and health pathways in the various EU MS”
- “Provision very much dependent on national HC/SC systems, regulations, intersectoral collaboration (e.g. is MoH and MoSA same or not? Therefore considerable differences exist amongst HCPs of the same ERN”
- “Mainly depends on organisation of care/social support at national/local level. Support of MoH is key. IC requires training of med and paramed teams, strong financial support needed”
- “Constraints in HC budgets in Low Income countries”
- “The social side of things delivered closer to patients. ERN itself not conceived to be primary point of care of patients – it is for advice”

'COMPLIANCE' (informally!) WITH THE RECOMMENDATIONS FOR CENTRES OF EXPERTISE AND ERNs

7.a) Does your Centre of Expertise/HCP:

Bring together, or coordinate (within the specialised healthcare sector) multidisciplinary competences/skills, including paramedical skills and social services;? *

- Yes
- No
- I do not know
- I am not associated with a particular HCP/CE

12 – Yes
1 – Not associated
2 – Did not know

7.b) Does your Centre of Expertise/HCP:

Provide education/training to non-healthcare professionals (such as social care practitioners, school teachers, personal/homecare facilitators)? *

- Yes
- No
- I do not know
- I am not associated with a particular HCP/CE

12 – Yes
1 – No
2 – Did not know

7. c) Does your Centre of Expertise/HCP:

Contribute somehow to the provision of accessible information on diseases/groups of diseases adapted to the specific needs of the following stakeholders (tick all that apply): *

- Patients/their families?
- Other health care professionals (e.g. primary care)?
- Social professionals (e.g. social workers, community services, teachers)?
- None of these at present
- I do not know
- I am not associated with a particular HCP/CE

7.d) Please provide examples of any successes/ good practices you wish to highlight and/or of any challenges you are facing re. the activities outlined in Q7 a,b and c above

11 – Yes to Patients/families

10 – Yes to Other health care professionals

8 – Yes to social professionals

Examples:

- On-site and online webinars for patient empowerment to make carers and non-health professionals aware of the RD topics (Blood HCP)
- Organised workshops for high school students and teachers, genetics for education and family (GENTURIS HCP)
- Nordic workgroups, conferences on patient care (difficult though as primary care very 'distant' to special care and v. limited resources for education)
- HCP paediatric but works closely with adult centre – transition of care a strength, and they offer social and teacher support where needed
- PO close working, produce info sheets, emergency cards, GP info, patient advisory days and workshops, Community visits (schools, care homes, houses) (EURO-NMD HCP)

8. a) Does your ERN collaborate with patient groups and social care providers? (Please tick all that apply) *

- Yes, my ERN collaborates with Patient Organisations/Patient Groups
- Yes, my ERN collaborates with Social Care providers
- I do not know

8. b) Does your ERN follow a multidisciplinary approach? *

- Yes
- No
- I do not know

8 c).Does your ERN function as a platform to share experiences and promote cooperation between Member States, to develop precise descriptions of the services (that is to say, holistic and social) required and elaborate common guidelines related to integrated/holistic care? *

- Yes
- No
- I do not know

14 – Yes, collaborates with POs

1 – Do not know

3 ERNs collaborate with social care providers : EYE, SKIN, Neuromuscular

14 – Yes

1 - No

9 – Yes

2 – No

4 - Do not know

Case Studies



EU Policy for Rare Diseases: the road to ERNs

- European policy for rare diseases has been focusing, for many years, on the advent of ERNs
- Having said this – there is a world beyond! Not all centres with expertise in a rare disease/specialised domain is formally part of an ERN, nor ever will be in many cases
- Need to think about what ERNs can offer in this sphere – but actually also, what CEs/HCPs can and should offer.

Guiding Discussion Questions

ERNs could perhaps:

- Spread understanding of the benefits of joined-up, holistic care pathways for patients (encompassing less strictly medical professionals, such as physiotherapists, psychological therapists, and social support appropriate to the specific needs of people with rare diseases and their families)
- Support and propel the drive to identify how best to provide care for patients with rare and complex conditions and define patient pathways (e.g. ERNs may help to define best practices and support their inclusion to comprehensive clinical practice guidelines or care guidelines)
- Create personalised health and social care plans for people with rare diseases, possibly both those receiving virtual referrals and the patients visiting constituent HCP
- Engage in tertiary prevention activities, including the creation of dedicated guidance from the ERN for patients and families and for local health and social actors (some activities may of course sit more logically with the actual Centres of Expertise i.e. the HCPs here)
- Embed good practices to support integrated care for patients in their constituent HCPs (and eventually 'affiliated' partners), and in time help to diffuse good practices to broader health systems
- Contribute to the collection and integration of data, to improve knowledge and understanding of rare diseases and the impact of patients and wider society

How to take things forward?

IT and Data-Sharing	Chair: Ruth Ladenstein, ERNPaedcan
Research	Chair: Eduardo López Granados, ERN TransplantChild
Legal Aspects, Data Protection and Ethics	Chair: Nicoline Hoogerbrugge, GENTURIS
Cross-Border Healthcare and Business Continuity	Chairs: Holm Graessner (ERN-RND) and Kate Bushby (EURO-NMD)
Monitoring and Assessment	Chair: Chris Chapple, EUROGEN
Guidelines, Education and Training	Chair: Paolo Casali, ERN EURACAN
Special projects; NHS Integration; Sustainability	Chair: Maurizio Scarpa, MetabERN

- What roles can we agree would be meaningful for ERNs and for HCPs respectively? Where do we want to be and what needs to be in place to do this? How much are these principles we want the HCP professionals to take on board and embed, which ideally they would be doing anyway?
- Do we need more recommendations for ERNs and holistic care?? Or just more concrete examples of what each might mean? Position paper on how and why ERNs could add value here.
- Do we need specific definitions for what Is and Is Not integrated and or holistic care, what is multidisciplinary ('care')? For the ERN context?
- What options might there be for ERNs to engage with social actors, with resource centres? Affiliated partners??
- How far do people see this CPMS being used for these sorts of IC and Holistic activities? What would need to be addressed for this?
- Will ERNs generate personalised care and social plans for patients 'discharged' from the ERN referral?
- How useful are the criteria ERNs came up with for what constitutes expertise in a disease area? Can ERNs define multidisciplinary teams better?
- Can ERN centres become like Vall d'Hebron and NoRo?

Qs for breakout

- Can ERN training duties include training of holistic care actors? Can we arrange this, as a few of the ERNs say they do??

Birute - with integrated care we must ensure:

- quality of care along the whole pathway: centralization of high-level, sophisticated, experience-required, expensive services in CEs and ERNs/ decentralization of other services for getting it closer to patients home (ensure safety!); guidelines and clinical pathway recommendations; information flow;
- timely access to all services: diagnostics – all solutions for undiagnosed diseases – truly undiagnosed and “stacked” in health systems; awareness-raising; medical education;
- coordination and responsibility: disease-specific – some are true orphans with no traditions; case managers – additional costs; patient organizations;

- patient-empowerment: raising of pro-active, responsible, educated patients, real partners in the game; involvement of communities;
- wide-spread, accessible, reliable information to all stakeholders involved: support to Orphanet, ERNs – both EU and national; goal – no excuse for “I don’t know”!
- fluent, timely flow of clinical/ patient information along the whole pathway: IT solutions;
- fluent transition pediatric – adult: collaboration of CEs; standardized procedures for transition, guidelines; special relevance for areas with traditional fragmentation (metabolic diseases);
- integrated in all meanings: along different medical situations (diagnostics-treatment-surveillance-rehabilitation-palliative care-pregnancy-emergency) – guidelines, awareness, involvement of all stakeholders; along all ages – transition, age-specific problems; family-oriented (support for families/ supporters)

Commission Expert Group

Recommendations to Support

Integration of RD into Social Policy

3. European Reference Networks for RD have a key role in facilitating integrated care provision in line with the EUCERD recommendations on European Reference Networks for Rare Diseases (10)23 and the Directive on patients' rights in cross-border healthcare:

- Rare Disease European Reference Networks (RD ERNs) need to collaborate with each other, as well as with patient groups, health and social care providers;
- RD ERNs follow a multi-disciplinary approach;
- RD ERNs could function as a platform to share experiences and promote cooperation between MS, to develop precise descriptions of the services required and elaborate common guidelines.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

1. The incorporation of RD specificities into mainstream social services and policies is a necessary element to be considered in future National Plans and Strategies (NP/NS) for RD and should be incorporated when existing NP/NS are evaluated and revised

Commission Expert Group

Recommendations to Support Integration of RD into Social Policy

2. Centres of Expertise have a key role in facilitating integrated care provision in line with the EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases:

- Centres of Expertise (CEs) bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services;
- CEs provide education and training to (...) non-healthcare professionals (such as school teachers, personal/homecare facilitators);
- CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals.

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

4. Member States (MS) should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights