



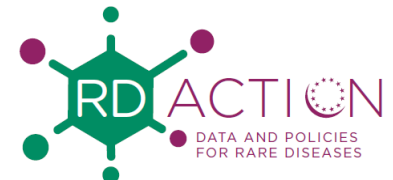
The 'Operationalisation' of ERNs

Victoria Hedley, RD-ACTION

victoria.hedley@ncl.ac.uk

This presentation is part of the project / joint action '677024 / RD-ACTION' which has received funding from the European Union's Health Programme (2014-2020).

The content of presentation represents the views of the author only and is his/her sole responsibility; it can not be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.



Where are we today?



– Coordinating HCPs based in 7 countries

Meet the Networks!

Network Name	Thematic Grouping	Coordinating HCP	Name of Coordinator
BOND	Rare Bone Disorders	Istituto Ortopedico Rizzoli, ITALY	Luca Sangiorgi
CRANIO	Rare Craniofacial anomalies and ENT disorder	Erasmus Medical Centre, Rotterdam - THE NETHERLANDS	Irene Mathijssen
ENDO-ERN	Rare Endocrine Diseases	Leiden University Medical Centre - THE NETHERLANDS	Alberto Pereira
EpiCARE	Rare and Complex Epilepsies	UCL Institute of Child Health - UNITED KINGDOM	Helen Cross
ERKNET	European Rare Kidney Diseases Reference Network	Heidelberg University Hospital - GERMANY	Franz Schaefer
ERN-RND	Rare Neurological Diseases	University Hospital Tübingen - GERMANY	Holm Graessner

<http://www.rd-action.eu/european-reference-networks-erns/coordination-of-rare-disease-erns/>

Who will benefit from ERNs?

- Many anticipated benefits, e.g.
 - For clinicians who network widely already, ERNs will formalise their networking structures/practices in highly specialized healthcare.
 - For those previously *without* specialist networking communities, ERNs will build capacity & coverage
 - For patients: ERNs should be a major equalising force, & should spread best practices
 - For industry: ERNs are ready-made expert communities, sitting at interplay of ‘care’ & ‘research’
 - For regulators, payers, HTA bodies: unprecedented access to expertise and experts

ERNs must possess/must demonstrate

- ✓ knowledge and **expertise to diagnose and manage patients**
- ✓ Evidence of **good outcomes**
- ✓ **multi-disciplinary** approach
- ✓ capacity to **produce good practice** and **implement outcome measurement**
- ✓ collaborate with **other CEs and ERNs**
- ✓ **Research, teaching and training**
- Each requires **robust connections between HCPs & ERNs**



Status Quo of virtual care in RD field

- What do you do at present, if struggling to find diagnosis, or treatment?
- Medical team
another expert
Send them ph
of p
- Informal – so
- Not secure, and possibly...
- And the knowledge created by that encounter stays between you and your colleague.



Exploring good practices for VC

- Workshop 27-8 Sept, Brussels
- <http://www.rd-action.eu/european-reference-networks-erns/>



Patient Pathways – not entirely clear yet

- Not self-referral; but how to complement and not threaten existing National Pathways is an issue
- Only complex cases should be subject of reviews – but *when you need it*, the service should be there
- ERNs need to be the ‘last port of call’ for Virtual MDTs BUT their HCPs arguably need to be 1st poc for everything else!
- **When patient cases DO enter that ERN sphere of ‘care’ they will need to be managed via a robust platform**

IT Platform – Status Quo?

- Lobbying for an appropriate platform: RD-ACTION, EURORDIS, and ERN leads (<http://www.rd-action.eu/wp-content/uploads/2015/12/What-do-Coordiators-require-from-an-ERN-ICT-platform.pdf>)
- Tender launched last summer for a SaaS
 - **Software as a service** = a **software** distribution model in which a third-party provider hosts applications and makes them available to customers over the Internet
- OpenAPP successful party, with Vitro
- However, platform being delivered by the EC
- First priority - safe, secure, working CPMS to exchange case information in virtual consultation/review

What we know?

dashboard

European Reference Networks | ERN

Map My Patients Panels doctor1 @ EB-Haus Austria -

EB-Haus Austria Doctor One

Dashboard

Enrol Patient

Patient List

User Management

Reports

Patients (ERN) 18 Patients

Enrol Patient

Patient List 18 Active patients

Search

First name, lastname or Ident Search

Recent Activity

Date	Study Id
18/04/2017 13:37	ERN-at01-001
12/04/2017 12:40	ERN-at01-018
12/04/2017 09:36	ERN-at01-017
11/04/2017 14:40	ERN-at01-016
11/04/2017 14:22	ERN-at01-015
10/04/2017 10:11	ERN-at01-014
09/04/2017 18:40	PATIENT 1
09/04/2017 15:56	ERN-at01-013
08/04/2017 14:40	1
07/04/2017 13:25	ERN-0001-002

How can we optimise this CPMS for RD/Highly Specialised Care?

- We know from the SaaS Tender that the data exchange/accessed for 1-to-1 care can be **stored/retained** by the CPMS
- All data will be Pseudonymised
- So potentially, hugely valuable repository of cases, for 'reuse'
- RD-ACTION has focused on demonstrating how this data can be optimised, and why this is necessary

Workshop on 'Exchanging Data for Virtual Care in ERNs' – 27-8th Sept '16

- Preceded by meeting of the ERNs and BoMS
- Explored options for 'virtual consultations' & garnered practical advice on organisation & execution



- Highlighted ELSI around data 'sharing'- especially in view of the new GDPR- and shared some existing good practices around consent in RD
- Clarified how patients might enter/ be 'referred' to the expertise of the ERN for virtual care
- **Shared experiences and began to identify recommendations on the standardisation of data in the RD field**

26-7th April: Workshop 'Using standards and embedding good practices to promote interoperable data sharing in ERNs'

- **Aim of the Workshop:** to analyse and demonstrate how ERNs and their associated experts can **use standards** to optimise the utility and reusability of clinical data, by sharing the state of the art of RD data standardisation practices.

Day 1 - **SoA of data-sharing for care in ERNs: Discussion session**

Day 2 – practical demonstrations and suggestions for use of

- **Orphanet Nomenclature and new OKMS**
- **HPO**
- **FAIR Data**
- **PPRL**

What we *don't* know

- Exactly what the finished product will look like
- How the video conferencing side will work – will it indeed cope with the types and size of files needed?
- Patient pathways yet to be confirmed – who enters data, under what circumstances?
- How much commonality there will be between data collected each time
- Whether the CPMS will, in time, offer any sort of registry – Not for foreseeable, besides v. basic record.
- Whether the data stored in the CPS will, in time, be linkable with robust existing registries
- If the platform will pseudonymise the patients in way we recommend
- **How patients will be able to access their own data in this CPMS, and perhaps contribute – PROMs are crucial**

ERN-related workshops

- **Exchanging data for virtual care in the ERN framework - 27-28 Sept 2016**
- **Using standards and embedding good practices to promote interoperable data sharing in ERNs - 26-27th April '17**
- **Indicators and Outcomes for ERNs (1-2 June) - Newcastle**
- **Exploring structured collaboration between ERNs and the Biopharmaceutical Industry, to support increased access to orphan therapies (Sept 26-27th, Barcelona)**
- **How can ERNs generate, appraise and utilise clinical practice guidelines, to enhance the impact and deployment of consensus guidelines in national health systems? (Dec 6-7th, Rome)**
- **Exploring the potential for Centres of Expertise and ERNs to provide integrated care for RD (2018)**
- **Exploring structured collaboration between ERNs, Regulators, HTA Bodies and Payers: Identifying points for collaboration in the OMP lifecycle (2018)**

Session 3: (After Lunch)

- MetabERN Focus Group will be held in Helia
- ITHACA Focus Group held in room Saturnus
- BOND Focus Group in room Venus