



European Reference Network

for rare or low prevalence complex diseases

ERN-ITHACA

 **Network**
Intellectual Disability and Congenital Malformations (ERN ITHACA)

One of 23 European Reference Networks For Rare Diseases



The ERN Process

- Priorities for reference networks set by EUCERD 2014
- ERN information meetings from 2015
- Bidding process April 2016 closed June 2016
- External assessment procedure
- Approved by Board of Member States December 2016
- ERN launch meeting Vilnius, March 2017
- Application for grant to run ERNs approval May 2017, 60% co-funded up to maximum €200,000

Participating Centres

- Coordinated by Manchester
- 38 centres from 14 member states
- Patient representation; E-PAGs/others
- Process for involvement of new members in the second wave being discussed, but should be within this first year
- Possibility to have affiliate HCPs who do not fulfil all criteria
- Involvement of other associated groups who are not Health care Providers e.g. EUROCAT

BOARD

SECRETARIAT



ADVISORY COMMITTEE

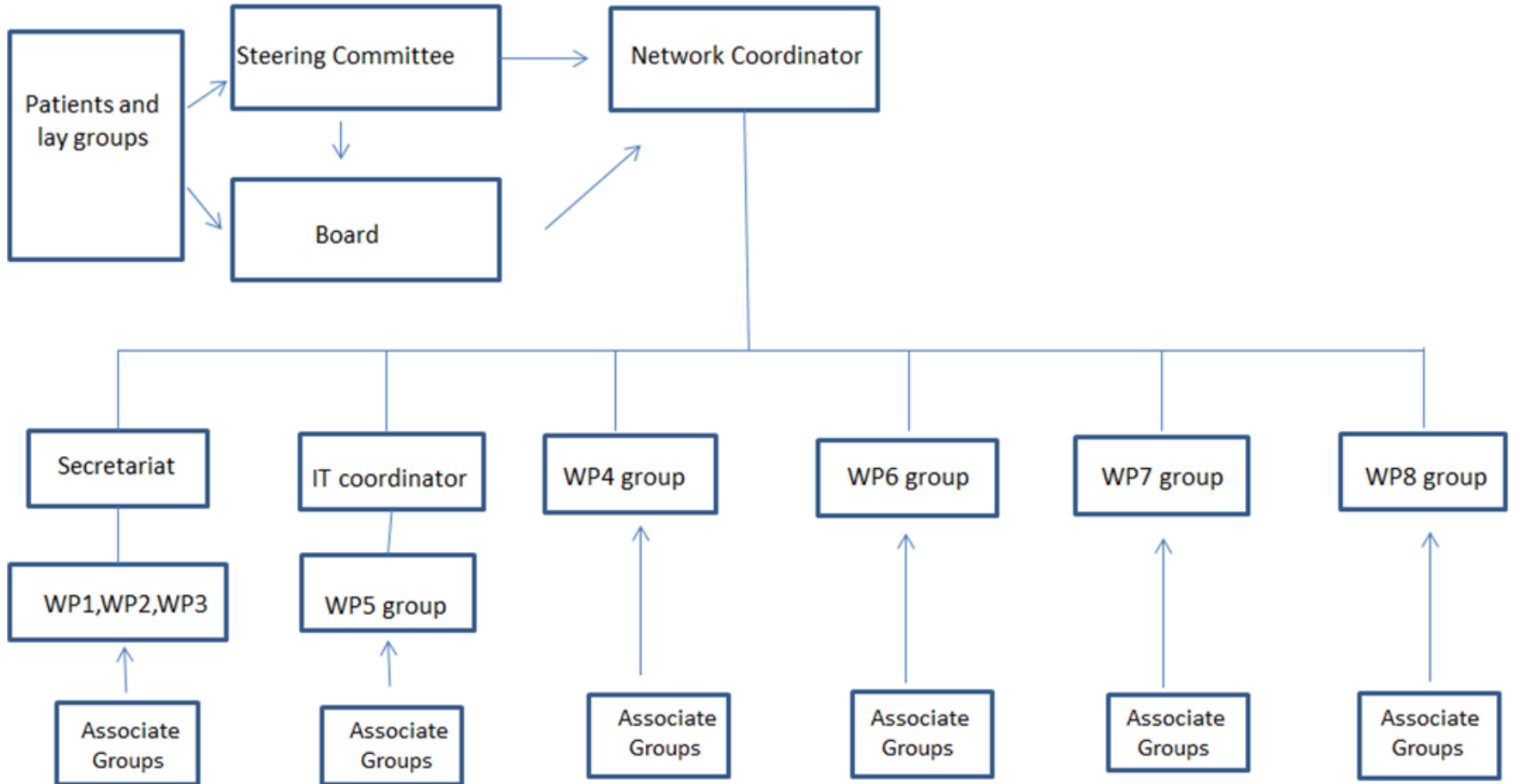
Interacting Networks

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Operational Structure



Mission Statement

We seek to provide a patient centred network which will meet the needs of those with rare congenital malformation and intellectual disability syndromes , both diagnosed and undiagnosed. We will provide an infrastructure for diagnosis, evidence-based management and collection of secure patient data. Members of the network will share best practice and disseminate guidelines to optimise and improve coordination of patient care. We will facilitate training, and capacity building in field, be active and collaborative researchers and work towards development of diagnostic tests and future therapies.

Our Vision

Working in Partnership With Patients We Will:

- Establish a functioning network
- Enhance provision of highly specialised multidisciplinary care
- Facilitate access to diagnosis using TeleHealth and other approaches
- Develop capacity to appraise and produce high quality guidelines
- Adopt, establish and curate high quality and secure patient registries
- Foster collaborative research and facilitate clinical trials
- Organise, deliver or facilitate access to a programme of teaching or training activities
- Collaborate with other ERNs, groups and centres of expertise

Guiding Principles

- **Patients will be at the heart of the ERN and care through the ERN should follow the patient and not vice versa**
- All HCPs who fulfil criteria can participate.
- All members are expected to contribute to activities and return data for monitoring purposes
- Outputs from our ERN should be free to access and widely disseminated
- Those in well-developed centres should be prepared to offer training opportunities to those in less well-developed centres
- All shared data should be secure and comply with the DPA
- Those working within the ERN should declare any conflicts of interest on an annual basis

The WorkPackages

- Management/Comms/Evaluation 1,2,3
- WP4 Expert Patient Care/Guidelines
- WP5 TeleHealth
- WP6 Patient Registries
- WP7 Research
- WP8 Training and Education

Objectives For Yr 1

1	Set up and run ERN	Posts recruited. All HCPs active by 6m No of WP with patients involved
2	Establish clear communication channels using IT	6 Teleconferences with minutes Website functional Report on website stats
3	Identify outcome measures	5-10 meaningful outcome measures defined
4	Define disorders where guideline exists and those where needed	Directory of existing guidelines published List of prioritised guidelines for development
6	Identify any existing patient registries	List of existing patient registries and details List of specific registries we have been involved or interacted with
7	Collaborate to add value to research currently being undertaken	Directory of research studies being undertaken within the ERN %age of those where there is collaboration
8.1	Collate and share current education/training resources	List of existing resources No of those who have utilised
8.2	Define unmet training/education needs	List of prioritised needs for parents and professionals

Currently:

- Posts for manager and admin help currently being advertised
- Launch meeting Manchester September 25th
- Pre-financing payment for running ERN arrived **THIS WEEK**
- Work already undertaken on most WP
- Board meeting and general meeting here at ESHG this week
- Many coordinators' and working group meetings

Challenges

- Large number of centres
- Administrative burden
- Limited finances
- Different languages
- IT
- New EU Data Protection Rules
- Brexit



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To be continued....

