

Table Of Content

European Reference Network for Rare Neurological Diseases - SGA	
years 3-5	3
Summary	4
Work Package	5
WP1 Coordination, management, communication and quality assurance of ERN-RND activities	5
Evaluation of ERN-RND activities	5
RND diagnostic pathway	5
Expert RND care coordination	5
WP5 Training, education and capacity building	5
Information sharing and disease resources	5
Guidelines, pathways and best practice	5
Registries and research	5
Coordinator, Leader contact and partners	8
Outputs	9
Generic diagnostic pathway for genetically caused RND	9
Recommendation for ERN-RND multidisciplinary teams	9
Framework report on cross-border pathways linked to the CPMS use	9
RND trial readiness report	9
Evaluation report based on defined indicators	9
Periodic communication reports	9
Report on set-up and pilot of CPMS use for external patients	9
Report on RND registry	9
Periodic reports based on dashboard for continuous monitoring of ERN-RND activities	9
Final ERN-RND report	9
Report on European Brain Council VoT case study for selected group of RND	9
Process on RND guideline development jointly with EAN, 3 guidelines of high priority produced	9
Directory of current recruiting research studies	9
Development plan of the network	9
Periodic reports on care quality indicators agreed on in ERN-RND	9
List of corrective actions, adapted portfolio of outcome measures	9
List of areas for RND and applied therapies with higher risk, and respective risk minimising strategies	9
Common ERN tool for measuring patient experience	9
Dissemination report and implementation result in ERN-RND	9
Report on EQA scheme(s) for genetic NGS RND diagnostics and pilot QA report	9
Report on use of CPMS for diagnostic cases from ERN-RND partners	9
Report on implemented awareness strategy for ERN-RND	9
Report on responding strategies	9
Reports on activities on additional care aspects like physiotherapy and Deep Brain Stimulaton for pediatric dystonia patients	9
Report of cross-ERN pilot case discussion in CPMS	9
Report on ERN-RND training and education measures	9
Web directory of training and education resources	9
Functioning website with updates, summary report of social media activities	9

Disease knowledge section on web site broken down to disease groups covered through ERN-RND	9
Web directory of relevant RND publications on ERN-RND web site	9
Draft recommendations for therapeutic algorithms for the disease groups covered by ERN-RND	9
List of ERN-RND endorsed or affirmed guidelines available on ERN-RND web site	9
Report on new ERN HCPs, associate centres and national coordination hubs	9
Social media based alert mechanism	9

European Reference Network for Rare Neurological Diseases - SGA years 3-5

JA2015 - GPSD [705038]

START DATE: 01/03/2019

END DATE: 28/02/2022

DURATION: 36 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Multiannual Grant Agreements for European Reference Networks

TOPIC: ERN Specific Grant Agreements 2019 - 2021

EC CONTRIBUTION: 600000 EUR

KEYWORDS: Care, Ehealth, Expertise Network, Knowledge Management, Rare Neurological Diseases

Project abstract

ERN-RND is a network of 32 Healthcare Providers from 13 EU member states. ERN-RND builds on existing expert centres and mature networks dedicated to rare neurological diseases (RND) as well as established rare disease infrastructures such as Orphanet, EURORDIS and RD-Connect. Through coordination and knowledge transfer, ERN-RND shall establish a patient-centred network to address the needs of patients with RND of all age groups, with or without a definite diagnosis, by implementing an infrastructure for diagnosis, evidence-based management, treatment and collection of patient data. The network will develop, disseminate, implement and supervise best practice guidelines and care pathways to optimize patient care and facilitate training and capacity building in the field. A special effort will be aimed to member states with less developed infrastructure for caring for RND patients, where no current partners are located, or with only affiliated or collaborative partners. ERN-RND will inform planning of European and national health care in RND, facilitating translation of research activities into clinical practice and the development of future therapies. Keeping in line with ERN-RND's strategic objectives the seven most important operational targets for year 3-5 are:

- Role-out of CPMS in ERN-RND for disease group specific use cases
- Define responding strategies for disease groups specific most important care needs for RND in the EU
- Implement EQA scheme for genetic diagnosis of RND
- Together with the European Academy of Neurology put in place process for development of RND clinical practise guidelines
- Implement ERN-RND training program consisting of training workshops, fellowships and e-learning
- Demonstrate value of RND registries for trial-readiness
- Establish ERN-RND web-site as THE European RND disease knowledge hub

Work package

Work Package 1: WP1 Coordination, management, communication and quality assurance of ERN-RND activities

Start month: 1

End month: 36

Work Package Leader: UKT

Activities:

Implement communication plan

Have a robust process in place to monitor activity

Create a forward-looking network with future potential

Coordinate and implement call for new ERN HCPs, link to associate centres and national coordination hubs

Work Package 2: Evaluation of ERN-RND activities

Start month: 1

End month: 36

Work Package Leader: UKT

Collate and analyse outcome measures

Plan, perform and monitor corrective actions

Develop and implement patient safety framework

Jointly with EURORDIS and other ERNs develop common tool for measuring patient experience

Work Package 3: RND diagnostic pathway

Start month: 1

End month: 36

Work Package Leader: UKT

Share and promote implementation of diagnostic RND flowcharts

Develop generic diagnostic pathway for genetically caused RND

Introduce and implement EQA scheme for genetic RND diagnostics

Share multidisciplinary diagnostic expertise in ERN-RND in a case-based manner

Plan and pilot CPMS use for diagnosis and care advice of external patients

Work Package 4: Expert RND care coordination

Start month: 1

End month: 36

Work Package Leader: UKT

Improve access to high quality care in terms of awareness of centres and disease knowledge

Respond to most important care needs of RND

Consent, share, implement and supervise standards of care regarding diagnosis and therapy

Working groups on additional care aspects that will profit from standardisation

Tight collaboration with other ERNs to improve care for RD patients

Review composition of multidisciplinary teams

Work Package 5: WP5 Training, education and capacity building

Start month: 1

End month: 36

Work Package Leader: UKT

Implement ERN-RND programme

Establish alert mechanism for rapid dissemination of NEW information

Improve access to educational resources

Work Package 6: Information sharing and disease resources

Start month: 1

End month: 36

Work Package Leader: UKT

Communicate effectively making use of IT

Improve provision of disease care resources to HCPs

Establish ERN-RND open access scientific library on care standards

Share experience of the added value of ERNs

Work Package 7: Guidelines, pathways and best practice

Start month: 1

End month: 36

Work Package Leader: UKT

Engage with European Brain Council's (EBC) Value Of Treatment (VOT) project
Improve patient care through use of high quality guidelines
Put in place a process for RD European guideline development
Develop cross-boarder pathways

Work Package 8: Registries and research

Start month: 1

End month: 36

Work Package Leader: UKT

Through establishment of the ERN, enhance research programmes, participation, uptake and publications
Expand scope of European RND registry
Demonstrate value of RND registries with regard to trial readiness

COORDINATOR



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PARTNERS

No partners related to the current project

Generic diagnostic pathway for genetically caused RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 02/09/2022

Generic diagnostic pathway for genetically caused RND

Recommendation for ERN-RND multidisciplinary teams

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 02/09/2022

Will be based on existing recommendation and will take into account work being done by ERN-RND

Framework report on cross-border pathways linked to the CPMS use

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 02/09/2022

Will be worked out for the linked national coordination hubs

RND trial readiness report

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 02/09/2022

Will be based on a series of workshops (co)organised through ERN-RND

Evaluation report based on defined indicators

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 02/09/2022

Indicators have been defined in the SGA. The fulfillment of these indicator will be assessed in a seperate report.

Periodic communication reports

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 25/08/2022

Based on multichannel ERN-RND activities

Report on set-up and pilot of CPMS use for external patients

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 23/08/2022

Set-up and pilot of CPMS use for external patients

Report on RND registry

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 23/08/2022

The aim is that this register includes information on genotype and time of last visit at ERN-RND centre

Periodic reports based on dashboard for continous monitoring of ERN-RND activities

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 22/08/2022

Based on BoM adopted document on continuous monitoring of ERNs

Final ERN-RND report

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 22/08/2022

Final report after years 1-5 of ERN

Report on European Brain Council VoT case study for selected group of RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 22/08/2022

This is a collaboration with the European Brain Council.

Process on RND guideline development jointly with EAN, 3 guidelines of high priority produced

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 22/08/2022

This is a collaboration with the European Academy of Neurology (EAN).

Directory of current recruiting research studies

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 22/08/2022

Will be included in disease knowledge section of web site

Development plan of the network

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5

(ERN-RND)

Published on: 21/08/2022

Will form the basis for the 2nd period application

Periodic reports on care quality indicators agreed on in ERN-RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be disease group specific

List of corrective actions, adapted portfolio of outcome measures

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

List of corrective actions, adapted portfolio of outcome measures

List of areas for RND and applied therapies with higher risk, and respective risk minimising strategies

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be disease group and service specific

Common ERN tool for measuring patient experience

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will depend on a respective EURORDIS led activity

Dissemination report and implementation result in ERN-RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Dissemination of diagnostic flowcharts and use of them at ERN-RND centres will be put into relation

Report on EQA scheme(s) for genetic NGS RND diagnostics and pilot QA report

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be done in cooperation with European Molecular Quality Network (EMQN)

Report on use of CPMS for diagnostic cases from ERN-RND partners

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be based on defined CPMS use cases

Report on implemented awareness strategy for ERN-RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Including google analytics of ERN-RND web site

Report on responding strategies

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Based on the care need survey being done in ERN-RND

Reports on activities on additional care aspects like physiotherapy and Deep Brain Stimulaton for pediatric dystonia patients

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Might be disease group cross cutting

Report of cross-ERN pilot case discussion in CPMS

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

ERN-RND will use established collaborations with Euro-NMD and ITHACA

Report on ERN-RND training and education measures

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be done in collaboration with the European Academy of Neurology and the Movement Disorders Society

Web directory of training and education resources

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be included in disease knowledge section of web site

Functioning website with updates, summary report of social media activities

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

The ERN-RND web site will undergo continuous development

Disease knowledge section on web site broken down to disease groups covered through ERN-RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

There will be a subsite per disease group

Web directory of relevant RND publications on ERN-RND web site

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 21/08/2022

Will be included in disease knowledge section of web site

Draft recommendations for therapeutic algorithms for the disease groups covered by ERN-RND

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 11/03/2021

Will be disease group specific

List of ERN-RND endorsed or affirmed guidelines available on ERN-RND web site

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 11/03/2021

Will be included in disease knowledge section of web site

Report on new ERN HCPs, associate centres and national coordination hubs

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 25/08/2020

Depends on implementation of call through BoM and European Commission

Social media based alert mechanism

UKT

European Reference Network for Rare Neurological Diseases - SGA years 3-5 (ERN-RND)

Published on: 24/08/2020

Will be Twitter based