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# EpiCARE – a network for rare and complex epilepsies

*HP-ERN-2016 European Reference Networks / Framework Partnership Agreement*

## D12.1. Report on existing rare epilepsy registries in Europe

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Lead beneficiary for this deliverable: *Professor Lieven Lagae*

Contributors: All 28 EpiCARE healthcare providers

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### Dissemination Level

PU	Public	X
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## 1. Version log

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Version	Date	Released by	Nature of Change
1.0	20/02/2018	Lieven Leage	First version

## 2. Definition and acronyms

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Acronyms	Definitions
ERDRI	European Rare Diseases Registry Infrastructure
ERN	European Reference Network

### 3. Introduction

EpiCARE aims to build a new registry for all rare and complex epilepsies for patients that are seen in the participating 28 EpiCARE centres. This database will be based on the ERDRI (European Rare Diseases Registry Infrastructure) guidelines and will therefore comprise not only epilepsy specific items, but also the 'common data set' that is common to all ERN databases. In order to understand what databases or registries already exist in the field of rare and complex epilepsies, we performed a survey within the 28 ERN centres.

The aim of the survey was to map up the following:

- (1) how many patients are already included
- (2) what the quality is of the existing databases is
- (3) how existing data eventually could be incorporated at a later stage in our new overall registry.

### 4. Activities carried out and results

#### 4.1. Activities

The following questionnaire was devised and circulated to all EpiCARE members in order to find out whether there are any specific databases or registries used (1) at the ERN members' own institution, (2) in their country and (3) at the European level for patients with rare and complex epilepsies. Furthermore, for each of the identified databases, a short description (type), and the number of patients included was asked as well as whether the database contains data for paediatric or adult patients or both.

<b>1. In your hospital/institute</b>	<b>Name/Type/Description</b>	<b>No. of patients included :</b>	<b>Children/Adults/Both</b>	<b>Comments:</b>
		1.	1.	
		2.	2.	
		3.	3.	
		...	...	
<b>2. In your country</b>	<b>Name/Type/Description</b>	<b>No. of patients included :</b>	<b>Children/Adults/Both</b>	<b>Comments:</b>
		1.	1.	
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3. In Europe	Name/Type/Description	No. of patients included :	Children/ Adults/ Both	Comments:
		2.	2.	
		3.	3.	
		...	...	
		1.	1.	
		2.	2.	
		3.	3.	
		...	...	

## 4.2. Results

### 1. **Hospital based registries.**

Detailed replies were received from 12 centres. Another 5 centres did reply that there was a local database, but without any further details. For the more detailed replies, it was seen that the number of patients included varied from 35 (local database on VNS) to >7500 (all patients attending epilepsy clinics). Many of these databases focus on one specific epilepsy syndrome/etiology.

### 2. **National level.**

The survey responses reported that the existence of 6 country specific databases: in Italy, Austria, Sweden, Poland France and Spain. Especially in Sweden and Italy, well established databases and registries are already available, covering a wide variety of epilepsy syndromes (surgery cases, Dravet syndrome, myoclonic epilepsies etc.)

### 3. **European level.**

More professional registries were seen at the European level. Some of the databases are already operational for many years and include many patients. Notable examples are the European Epilepsy Brain bank (pathology), E-epilepsy (surgery), Epi25 (genetic), Eurap (epilepsy and pregnancy), Residras (genetic).

The detailed list of databases and registries from the local, national and European level including the number of patients is enclosed at ANNEX 1.

## 5 Conclusions

It is clear from this survey that many, if not all, local hospitals have some form of a database consisting of their own patients. These are very variable content-wise and range from just listings of patient names to a complete database including a follow up part for use in everyday clinical practice. Depending on local scientific interest more specialised databases are constructed with limited number of patients. Some of these databases could serve as a more global European database in the future. There is a considerable lack of national registries (with perhaps the exception of Italy and Sweden). The best and more professional registries are at the European level. When we build our new registry, we will have to link to these existing European databases and harmonise the already existing information in order to be able to incorporate the already existing information on rare epilepsy patients.

### ANNEX 1.

	No of patients included :
1. Epilepsy surgery database: all patients operated on at Meyer Hospital	1. 180
2. MCD database: all patients with MCD evaluated at Meyer Hospital	2. 1600
3. Epileptic Encephalopathies database: all patients with EE evaluated at Meyer Hospital	3. 400
4. Epilepsy database: all patients with epilepsy evaluated at Meyer Hospital	4. 4000
5. CNVs database: all patients with CNVs evaluated at Meyer Hospital	5. 350
1. Epilepsy Outpatient Clinic	1.approx. > 2.000
2. "e-pilepsy surgery Database"	2.
3. HEP - Human Epilepsy Project	3.
Epilepsy patients attending clinic	7845
Epilepsy surgery	987
1. A <b>national</b> Dravet syndrome registry	1. 48 children
2. Ketogenic diet	2. 50 children
3. VNS children	3. 35 children
4. VNS adults	4. 247



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We do have databases for disease-specific epilepsies, like TSC, cortical dysplasias, etc)

German Neuropathology Reference Center for Epilepsy Surgery	7165
Epilepsy Surgery DB	More than 200
Psychiatric DB	More than 100
MORE register	15
My sanità (clinica record for outpatients)	2567

Local Data-Base for patients with genetic investigations (NGS)	to be updated
Institutional software for digitizing all medical report	760; to be updated
annual data base of patients admitted in Pediatric and adult department (since 2015)	834, to be updated
RE and autoimmune encephalitis with detected antibodies	73
patients undergone surgical procedure for epilepsy	303
patients with mutations of PCDH19 gene	10
	44
	7

GRENAT	1505 adults
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Epilepsy Unit Database	499
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TSC database	180
ESES database	100
epilepsy surgery database (including all pts evaluated)	
SCN1a database	200

Name/Type/Description	No of patients included :
Tuscany Registry of Rare Diseases	967
ESBACE (Aarhus-University)	approx 90 for AT - total 782
1. BEpQ (National Child Epilepsy QoL Registry)	1. 1300
2. SNESUR (Swedish National Epilepsy Surgery Register)	2. 1455
3. EP-reg (Swedish Adult National Epilepsy Register)	3. 1044
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EURAP (international registry on pregnancies)	23803
1.Regisiter for PME patients and essential myoclonus	224
3. Myoclonic Epilesies	to be updated
2. Dravet, SCN1A, PCDH19 registries	
GRENAT	9639
Health Ministry Register for epilepsy surgery	Unknown
<b>Name/Type/Description</b>	<b>No of patients included :</b>
1.E-pilepsy registry: patients operated on for drug-resistant seizures	1. 15 from Meyer Hospital
2. Residras registry: International Registry of Dravet Syndrome and other Syndromes correlated with genes on SCN1A and PCDH19.	2. 50-60 from Meyer Hospital
1. EURAP Pregnancy Register	1.
2. EuroNASH (European Audit of Seizure Management in Hospitals)	2. 250
3. EEBB - European Epilepsy Brain Bank	3.
4. SNSE - Status-Epilepticus Register (A, D, CH)	...
NOPRES (Nordic Prospective observational study of outcomes after Rare Epilepsy Surgery procedures)	21 children
European Epilepsy Brain Bank	9523
MORE register	more than 150
Epi 25	307
European Brain Bank	
EURAP epilepsy and pregnancy	23554
European network on alternating hemiplegia	...