



**European
Reference
Networks**



VASCERN 1st Annual Seminar

Paris, France

13-14 October 2017

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Jean Marie Misztela**

**DG SANTE
European Commission**

*Health and
Food Safety*



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The rationale behind



- Many patients affected by a **rare or complex condition** do not have **access to diagnosis** and high-quality treatment.
- Expertise and **specialist knowledge** may be **scarce** because patient numbers are low
- **No country alone** has the knowledge and capacity to treat all rare and complex diseases.
- **Important delay in diagnosis** because lack of knowledge or right referral systems
- **Lack of diagnostic capacity** (no tests available) and treatments in many cases



Outcome call 2016



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24



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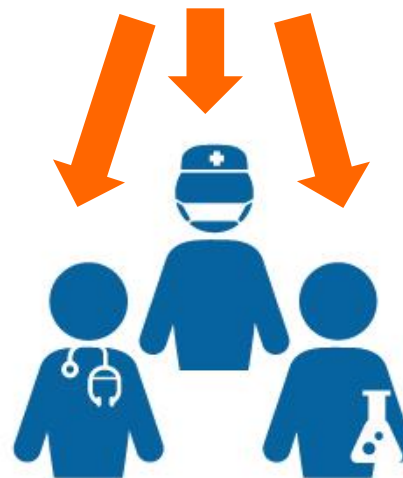
Networks

26 COUNTRIES



> 300
HOSPITALS

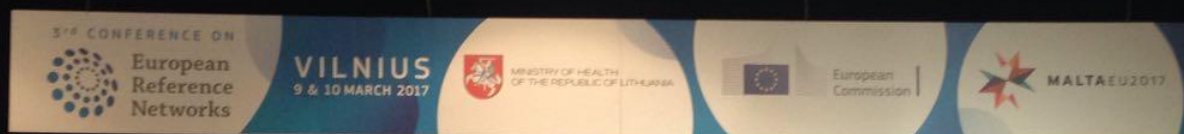
Full
Member



> 900
HEALTHCARE UNITS

Health and
Food Safety

AWARD CEREMONY
3rd European Reference Networks Conference
9 March 2017 - Vilnius, Lithuania





BOND ERN	Bone Diseases	EuroBloodNet	Onco-Hematological Diseases
CRANIO	Craniofacial anomalies and ENT disorders	EUROGEN	Urogenital Diseases
Endo-ERN	Endocrine Conditions	EURO-NMD	Neuromuscular Diseases
EpiCARE	Rare and Complex Epilepsies	GUARD-HEART	Diseases of the Heart
ERKNet	Kidney Diseases	ITHACA	Congenital Malformations and Intellectual Disability
ERN GENTURIS	Genetic Tumour Risk Syndromes	MetabERN	Hereditary metabolic diseases
ERN-EYE	Eye Diseases	RARE-LIVER	Hepatological Diseases
ERNICA	inherited and congenital anomalies	ReCONNET	Connective Tissue and Musculoskeletal Diseases
ERN-LUNG	Respiratory Diseases	RITA	Immunodeficiency, AutoInflammatory and Auto Immune Diseases
ERN-RND	Neurological Diseases	TRANSPLANT-CHILD	Transplantation in Children
ERN-Skin	Skin Disorders	VASCERN	Multisystemic Vascular Diseases
ERN Paedcan	Rare Paediatric Cancers		
EURACAN	Solid Adult Cancers		

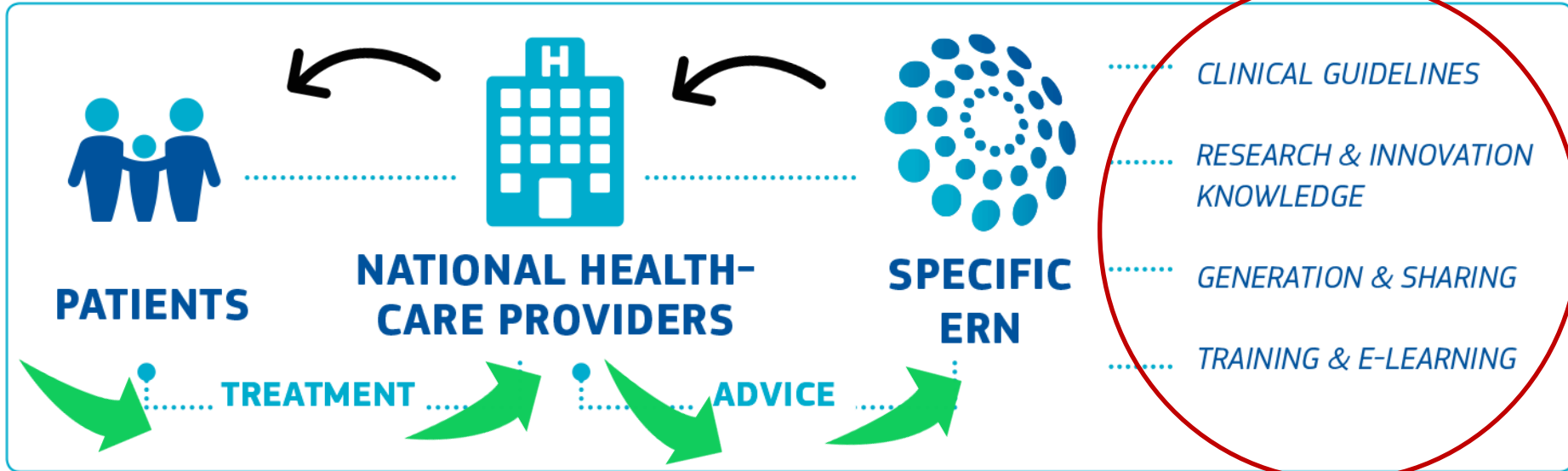
Share. Care. Cure.



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**Clinical
virtual care**

Research

Knowledge generation

Phases of the ERN life cycle



2011-14

Legislation and initial planning

Directive
Implementing decisions
Awareness and communication

2015-16

Implementation: (Approval stage)

Design and development
Assessment tools
Call for ERN
Assessment of Network proposals
Approval of ERNs

2017-18

Implementation: (deployment stage)

Establishment
Initial organizational phase
Functioning (initial actions and services)
Partial service production



2019-20

Consolidation

Full service production
Continuous monitoring
Performance indicators and initial outcome assessment

2021

Evaluation and update

project cycle re-initiation



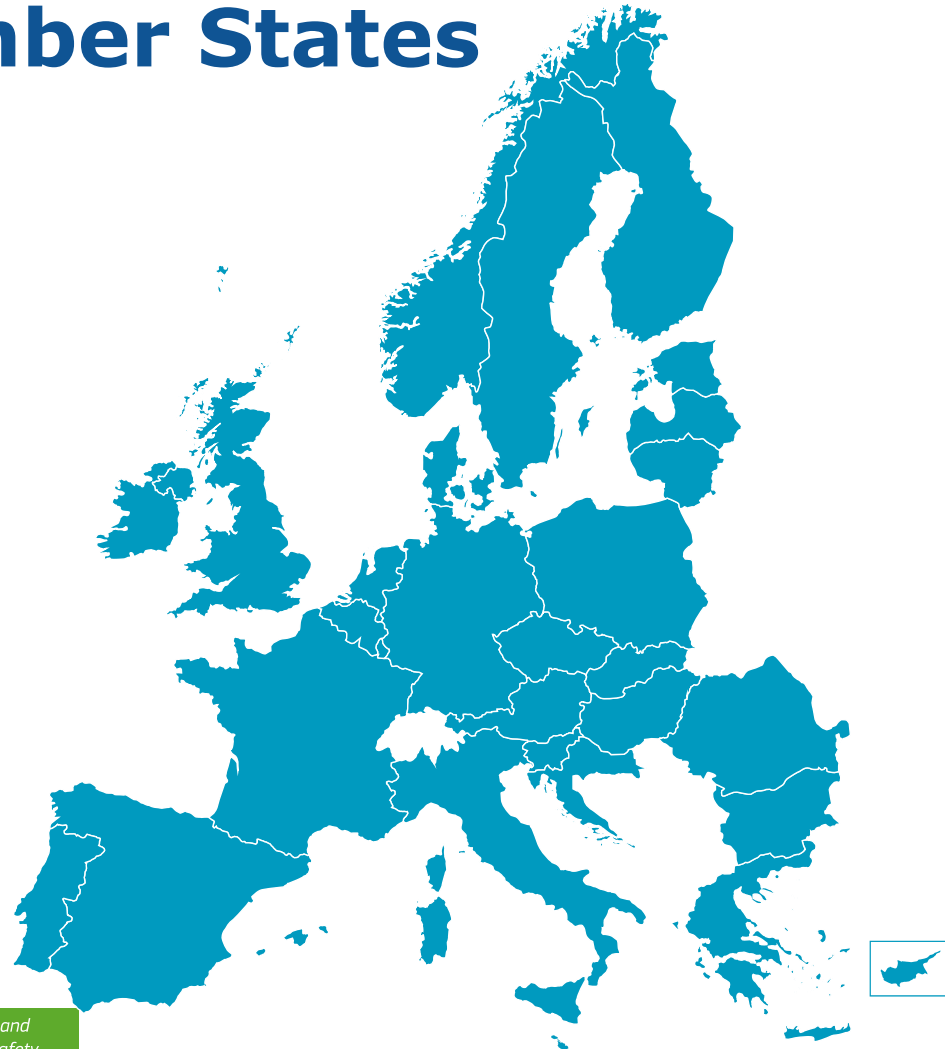
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Key role of the Member States

- Recognition of HCP or centers of expertise at national level
- Endorsement of applications
- Board of Member States
 - Development EU ERN strategy
 - Approval of Networks (once positively assessed)





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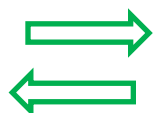
Actors involved in the ERN implementation



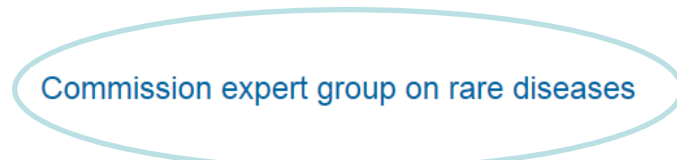
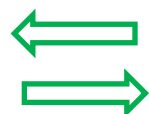
ERNs' Coordinators



European Reference Networks



ERNs BoMS



Commission expert group on rare diseases



Patients organisations



Professional / scientific organisations



DG SANTE

- DG CONNECT
- DG RTD
- JRC
- DG DIGIT
- INEA
- CHAFEA

Health and Food Safety



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What's on the discussion table?



ERNs BoMS



ERNs' Coordinators

- **Monitoring** ↔ • **Monitoring**
- **Information System** ↔ • **Information System**
- **Affiliated partners** ↔ • **Cross Borders and Business continuity**
- **Relationship with Industry** ↔ • **Ethics**
- **Integration with National healthcare systems** ↔ • **Research**
- **Knowledge generation**



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Workshop

Role of Hospital Managers in Shaping the Future of the European Reference Networks

- To better understand the **benefits and impact** of the ERNs and its Members in the Hospitals host of the ERN Coordinators and Members.
- To identify best practices and possible actions of Hospital Directors and CEOs to **support the ERNs members**.
- To **align goals and activities** in a win-win patient centered strategy of ERNs, Member States and Hospital managers.
- To discuss **future actions**, links and next steps.

Date: 17 November 2017

Venue: Erasmus University Medical Center Rotterdam

If interested send an email to: SANTE-COORDINATORS-ERN@ec.europa.eu



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Expected impact of the ERNs for patients and professionals

- ✓ improve **public and professional awareness** of rare and complex diseases
- ✓ increase the **likelihood of early and accurate diagnosis** and **effective treatment** where available.
- ✓ platforms for the **development of guidelines, training and knowledge-sharing.**
- ✓ facilitate **large clinical studies** to improve understanding and develop new drugs
- ✓ An **opportunity for networking** with likeminded experts from across Europe — **ending the professional isolation that many experts in rare diseases face.**



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Expected impact of the ERNs for the Healthcare systems and society

- ✓ **Innovation** in healthcare delivery is the cornerstone of the ERN system
- ✓ Incubators for the development of **digital services** for the provision of virtual healthcare.
- ✓ Development of **new care models**, and innovative medical solutions and devices, changing the way in which treatment itself is delivered.
- ✓ Will help to **boost economies of scale** and ensure a more efficient use of resources, with a positive impact on the sustainability of national healthcare systems.



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Pre-publication of Horizon 2020 SC1 Draft Work Programme 2018-2020

EN

Horizon 2020

Work Programme 2018-2020

8. Health, demographic change and wellbeing

Important notice on the Horizon 2020 Work Programme

This draft has not been adopted or endorsed by the European Commission. Any views expressed are the views of the Commission services and may not in any circumstances be regarded as stating an official position of the Commission.

This draft is made public before the adoption of the work programme 2018-2020 to provide potential participants with the currently expected main lines of this work programme. Only the adopted work programme will have legal value.

The adoption of the work programme will be announced on the Horizon 2020 website and on the Participant Portal.

Information and topic descriptions indicated in this draft may not appear in the final work programme; and likewise, new elements may be introduced at a later stage. Any information disclosed by any other party shall not be construed as having been endorsed by or affiliated to the Commission.

The Commission expressly disclaims liability for any future changes of the content of this document.

**Rare Disease European Joint
Programme Cofund
SC1-BHC-04-2018**

**Innovation Procurement: Next
generation sequencing (NGS) for
routine diagnosis
SC1-BHC-10-2019**

**HTA research to support evidence-
based healthcare
SC1-BHC-26-2018**

**+ other topics offering rare disease
funding opportunities**

https://ec.europa.eu/programmes/horizon2020/sites/horizon2020/files/vs.10.2_f_or_pre-publication_h2020-sc1-2018-2020_10_09_2017.pdf

3 ERN IT TOOLS : 3 Objectives

European collaborative Platform (ECP)

Facilitate Networking between HP's

Circabc

***Share documents between restricted
workgroup members***

CPMS

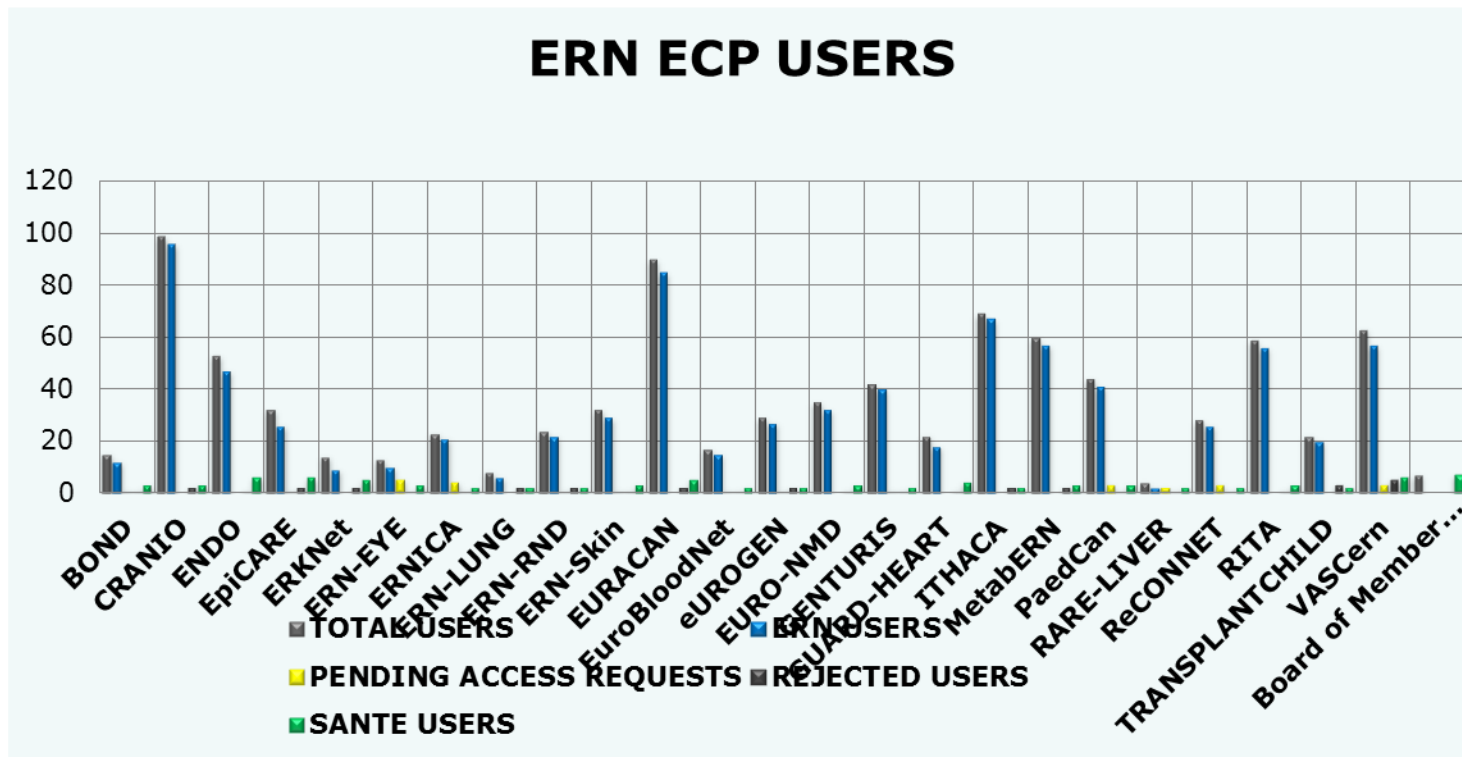
Support in the Diagnosis & Treatment



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Report on ECP platform usage

- From 533 in June to 1303 users for 24 ERNs in October
- 607 helpdesk tickets (mainly for access request)

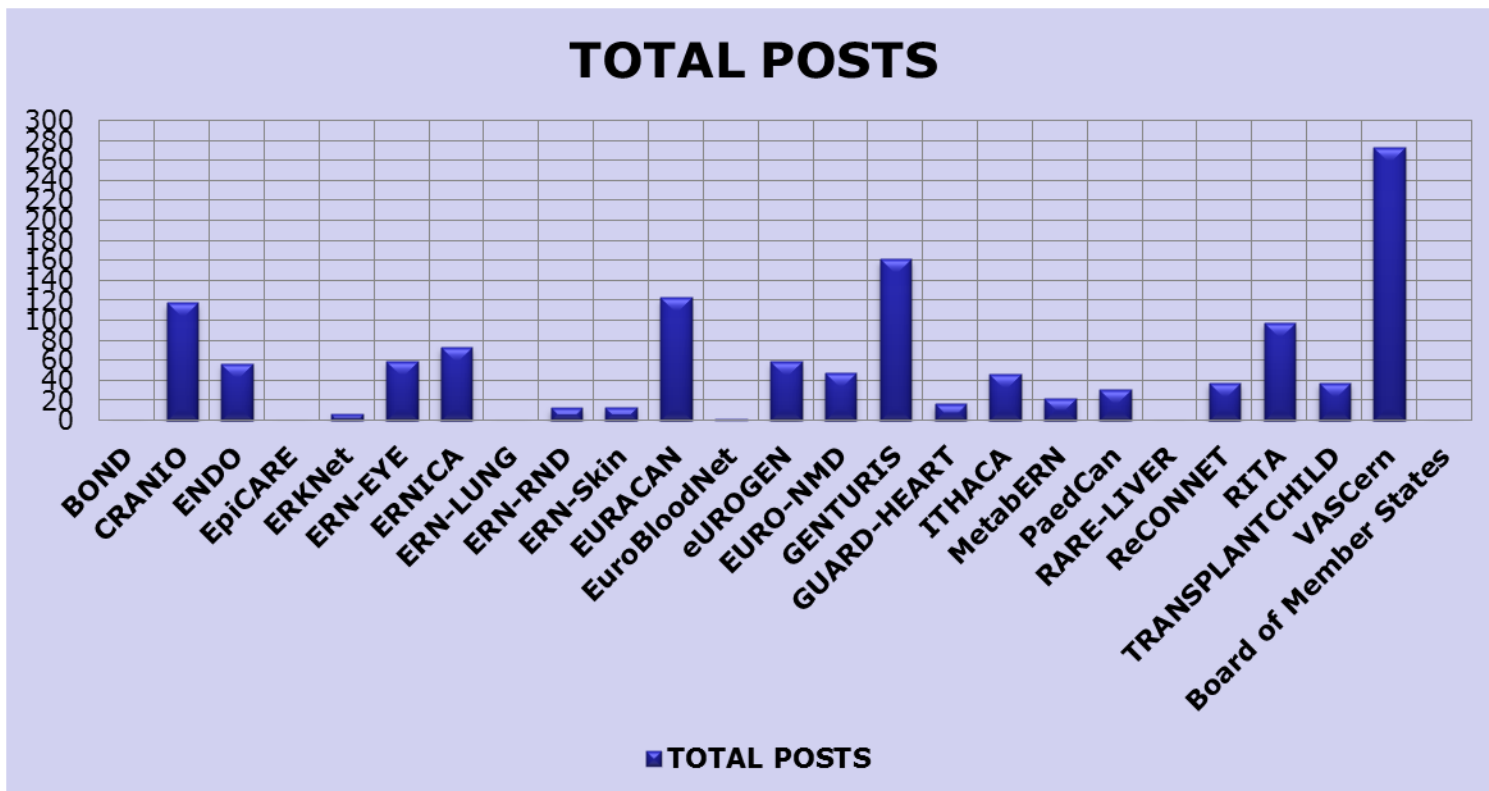




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Report on ECP platform usage

- *Posts per ERN*

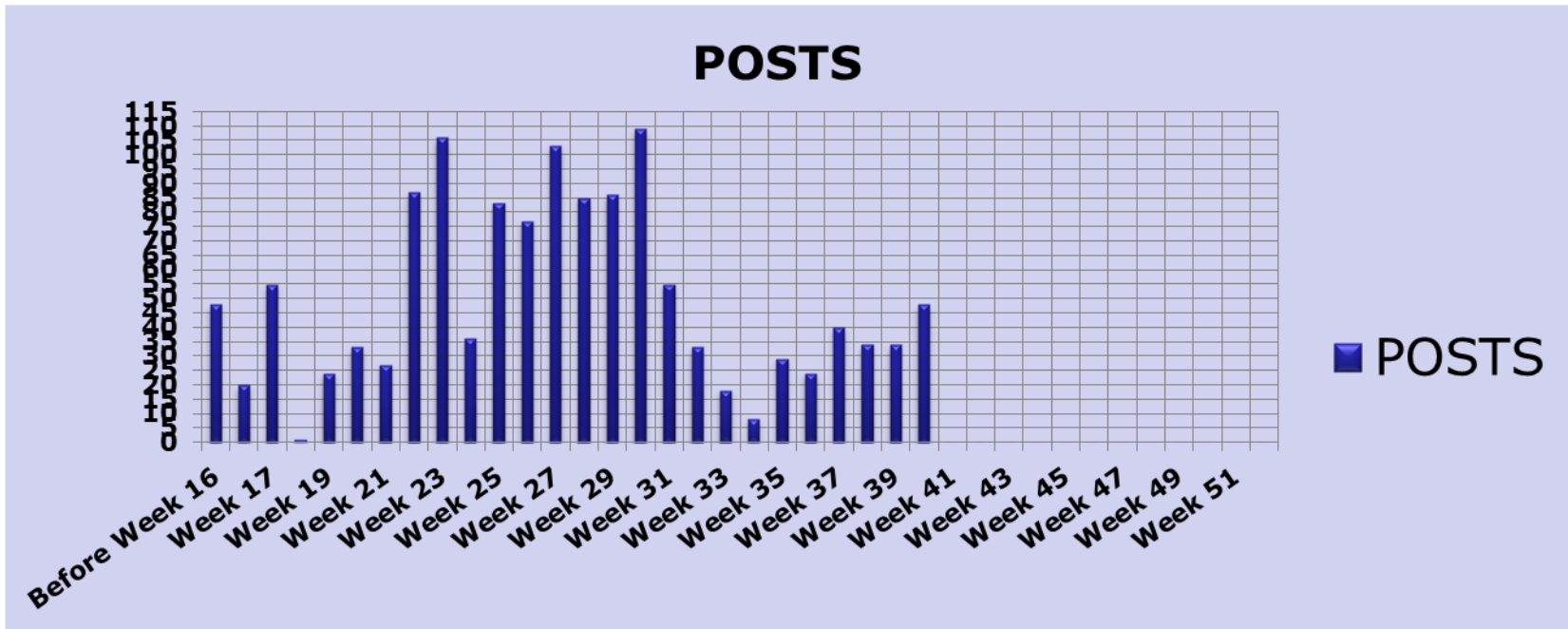




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Report on ECP platform usage

- *Activity for the past 6 months 1228 posts*



Webex VideoConference Tool experience feedback (ECP only)

- *from 3 experiences in June to 120 experiences 10th of October*
- ***Lessons learned***
 - **Confirmation of Importance of Preparation and Guidelines reading**
 - Component installation
 - Audio settings / muting
 - Directions from the meeting chairman are important
 - Best practices/guidelines.
 - **TEST BEFORE THE MEETING**

ERN Collaborative Platform

Document Management System solution request analysis and assessment

- **23/04 request**
- **CIRCABC implemented**



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CIRCABC

(from summer 2017)

Objective

- Share documents between restricted workgroup members

Beneficiaries

- Restricted to ERN users only

Key functionality

- Share and manage documents between users

Features

- Library

European Commission | CIRCABC

EUROPA > European Commission > CIRCABC > European Reference Network > ERN GUARD-HEART

ERNGUARD-HEART

Information

Library

- ▶ Add content
- ▶ Create space
- ▶ Add URL
- ▶ Import
- ▶ Bulk operation

Members

Events

Newsletters

Administration

Search

Advanced Search

Clipboard

Main Menu

- ▶ Browse categories
- ▶ Logout (password)
- ▶ Help
- ▶ CIRCABC online training course

Library

The library is the space where contents are stored, managed and shared.

In the library service, users manage and share their documents

Spaces

Title	Modified Date
Congenital Heart Disease	21 September 2017 14:51
Data Management and E-health	21 September 2017 14:53
Ethics and policy issues	21 September 2017 14:52
Familial Cardiomyopathies	21 September 2017 14:50
Familial Electrical Diseases	21 September 2017 14:51
Knowledge management	21 September 2017 14:52
Other rare cardiac disease	21 September 2017 14:52
Research and Funding	21 September 2017 14:53
Special Electrophysiology Conditions	21 September 2017 14:52
Teaching and E-Learning	21 September 2017 14:53

Content

Name	Size	Modified Date
No items to display.		

2. Clinical Patient Management System

- *Clinical Patient Management System is the only official ERN patient management tool, critical for:*
 - **patient care, diagnosis and treatment;**
 - **Virtual meetings to discuss and prepare outcome an**
 - **future clinical research.**
 - **Collaborative on-line tools**
- *The focus is first on diagnosis and treatment for patients by providing tools for collaboration, virtual consultations.*



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2. Clinical Patient Management System

- **First-line support in the Commission (DG SANTE) Done**
- **Second-line support with service provider Done**
- **User accounts in EULogin system, synchronised to CPMS by DG SANTE Done**
 - **User authorisation controlled and managed by ERN coordinators/HCP Representatives, implemented by SANTE support To be Done**
- *Commission will communicate service information whenever necessary*



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2. Clinical Patient Management System

- *Roll-out steps Done*

1. Acceptance testing by DG SANTE in July 2017
Done
2. Once accepted, pilot testing by ERN's, test data until data protection notification is approved.
Done
3. For pilot testing: Users need to be authorised and registered in the ERN-CPMS, co-ordinators should ensure this happens correctly, otherwise test account only **Done**
4. After successful pilot and DPO issues resolved, open for production-deployment. **Done**
5. Training material will be prepared and consultant available to support. **Done**

Data Protection

- *Aimed to be fully aligned with the EU current and GDPR (EU Member States have to transpose it into their national law by 6 May 2018, for application by **25 May 2018**).*
- *Status :*
 - **ECP notification done (for information)**
 - **CPMS notification : prior check underway, expected to be finished end of October**

