



# European Reference Networks: strategic value for the Member States

## Perspective of France

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II European Reference Networks Conference  
Lisbon 8-9 October 2015



## European Reference Networks:

- Networks of **healthcare providers/centres of expertise**
- Improving **access to highly specialised healthcare for patients/conditions** requiring a **particular concentration of expertise**
- **Rare**, or low prevalence, and **complex diseases**
- **Rarety** : diseases/patients; experts; facilities/technical supports
- **Complexity** : diagnosis or treatment or management and high cost of the treatment and resources involved
- **Multidisciplinary approach** and **well-planned organisation** of services
- **Patient-centred, Informed consent, Rights of the patients**
- Any group of **at least 10 healthcare providers** established in **at least 8 MSs**

## Roles of MSs?

- **Nomination** of centres of expertise (CEs)
- **Information of CEs** about the procedure of ERN creation and the future public call for interest
- **Fostering participation** of existing CEs to ERNs (to ERN proposals and later to existing ERNs): however, **the participation of CEs is voluntary**
- **Endorsement** of each CE applicant to a ERN proposal before its submission to DG SANTE : the participation if the CE “ is in accordance with the MS national legislation regarding licensing, accreditation, commissioning, and certification. “

## Roles of MBs ?

### Nomination of centres of expertise: French organisation

- **Rare diseases:**

- **During the 1st National Plan for RDs (2005-2008):**

- 133 « centres de référence maladies rares » (CRMR), in fact 380 sites in Academic Hospitals
    - 501 « centre de compétences maladies rares » (CCMR)

- **During the 2<sup>nd</sup> National Plan for RDs (2011-2016):**

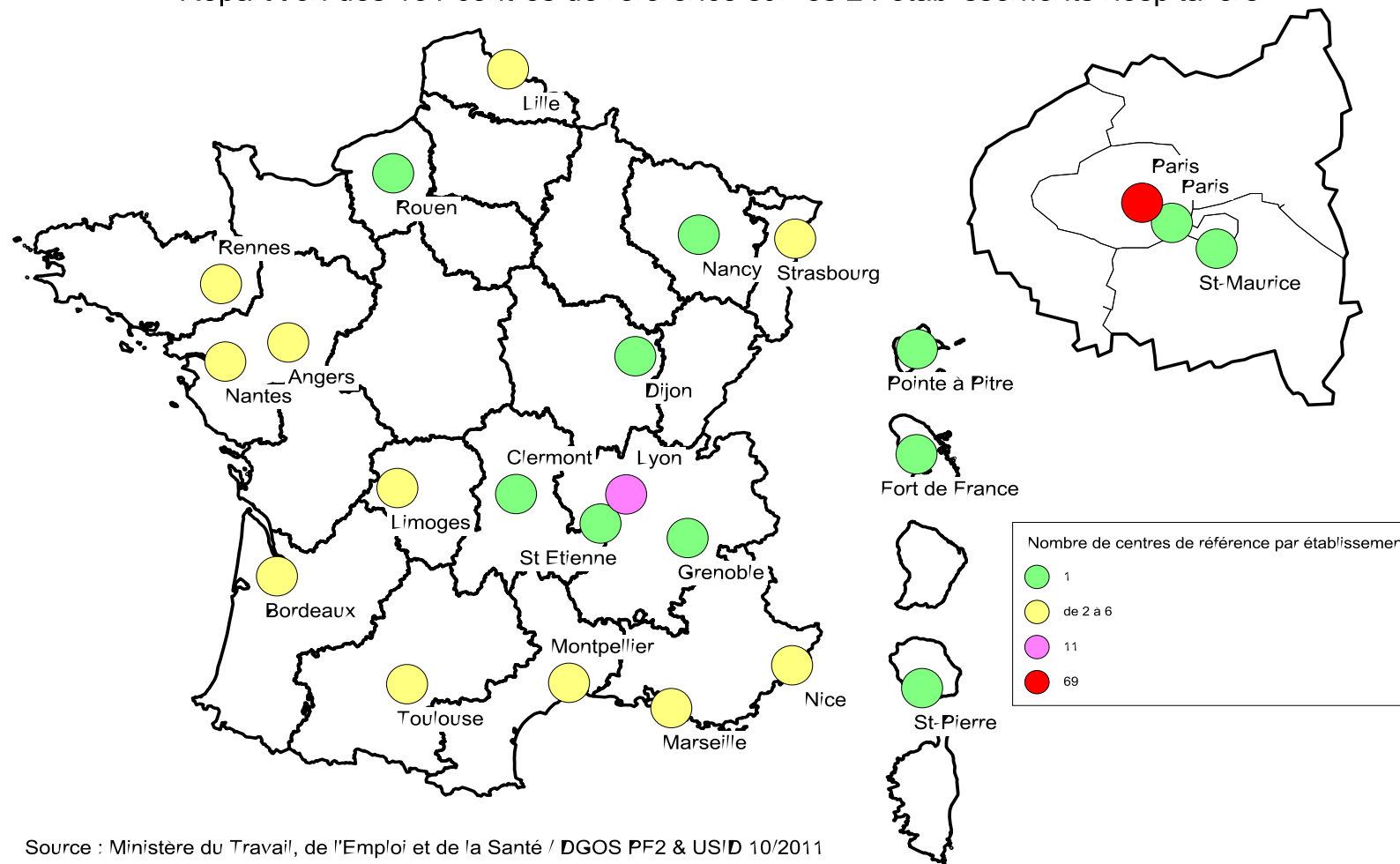
- 23 « filières de santé maladies rares » (FSMR): national networks (115 out of 133 CRMR)

- **Rare cancer in adults:**

- **During the 2<sup>nd</sup> National Plan for Cancer (2009-2013):**

- 22 National Networks
    - 4 National Anatomico-pathological Networks

## Plan National Maladies Rares 2011-2014 (PNMR) Répartition des 131 centres de référence sur les 24 établissements hospitaliers





Network « ANDDI-Rares »:  
 « Developmental abnormalities,  
 malformative syndromes &  
 intellectual disabilities »

## Roles of MBs?

### Fostering participation of CEs to ERNs: French experience

- **Information of CEs:** FSMRs, Réseaux cancers rares
- **Many issues at the moment:**
  - How to identify healthcare providers/CEs in EU aiming to build a common proposal?
  - ERNs for healthcare or for research?
  - Practical consequences for the patients/their families?
  - Grouping of diseases in ERNs: relevance?
  - Roles of members and coordinator in ERNs?
  - Participation or coordination?
  - Extra workload due to ERN?
  - Availability of the ERN evaluation manual and tools?
  - Availability for the call of interest, procedure and calendar?
  - Fundings and practical tools?
  - ....
- **Endorsement of each CE for application :** work in progress within MoH/INCa

## Why to participate to ERNs ?

Each ERN must have at least 3 of the following 8 objectives (Art. 12):

- **European cooperation** : innovations in medical science and health technologies
- **Pooling of knowledge** regarding sickness **prevention**
- **Improvements in diagnosis** and the **delivery of high-quality, accessible and cost-effective healthcare** when expertise is rare
- Maximising the **cost-effective use of resources** by concentrating
- **Reinforcing research, epidemiological surveillance** like registries and providing **training** for health professionals

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- **Facilitating mobility of expertise**, virtually or physically, and developing , sharing and spreading **information, knowledge and best practice** and **fostering developments of the diagnosis and treatment of rare diseases**, within and outside the networks
- Encouraging the development of **quality and safety** benchmarks and helping develop and spread best practice within and outside the network;
- **Help for MSs** with an insufficient number of patients with a particular medical condition or lacking technology or expertise **to provide highly specialised services of high quality.**

## ERNs: expectations and challenges

- **Improvement of diagnosis, treatment and research** thanks to the extension of the number of patients and **sharing expertise (supply and demand)**
- **Common best practices and improvement of quality of care in EU**
- **Improvement of equity in healthcare in EU**
- **E-health**

**Still many challenges and many questions!**

**Pioneering spirit!**

# Thank you for your attention

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