

## "IMPROVING INTEGRATED CARE FOR RARE DISEASE PATIENTS WITHIN THE EUREGION MEUSE RHINE"

START  
PROJECT  
**2016**

END  
PROJECT  
**2020**

**1**

### INTRO

Approximately **6,000** to **8,000** distinct rare diseases (RD)

**27 to 36 million** EU-citizens are affected, 300.000 (often children) in the Euregio Meuse-Rhine (EMR)

Still **difficulties** in giving or getting the **correct diagnosis**, treatment, care, financial and administrative support

Expertise is **geographically scattered**

### Ambitions of EMRaDi:



Develop **solutions** for optimized RD patient pathways



Make the provision of **relevant information** more effective



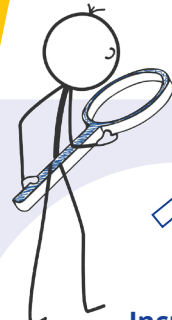
Improve **networking** and **training** related to rare disease care



To make substantive improvements in integrated care for rare disease patients, University Hospitals, health insurance funds, patient organizations and a University within the EMR have joined forces, resulting in **EMRaDi**.

**2**

### 3 MAIN OBJECTIVES AND 5 WORK PACKAGES TO ACHIEVE THEM



**1**

**Increase transparency of needs and availability of services in the field of rare diseases**

**WP1** Evaluation of supply and demand in the field of rare diseases in the Euregio Meuse-Rhine:

- Report on the demands and needs of patients (literature review)
- Evaluation of the number of patients with rare diseases
- Analysis of legal, financial and reimbursement mechanisms of rare diseases for treatment costs of EMR rare diseases patients

**WP2** Field analysis of existing rare disease patient pathways

- Field analysis report of existing RD patient pathways in the EMR
  - based on the experience of 104 interviewed participants to uncover the day-to-day reality of RD patients and their relatives

**2**

**Develop EMR models of RD patient pathways in order to elaborate patient-oriented recommendations in synergy with national and European developments**

**WP3** Development of organizational models for the management of rare diseases in the Euregio Meuse-Rhine

- Patient-oriented models of good practices for the management of rare diseases, with
  - generic and specific organisational models in border regions
  - recommendations for national and European developments



**3**

**Improve the network of healthcare providers, health insurance providers and patient organizations, and raise (public) awareness for rare diseases**

**WP4** Networking, training and exchanges of expertise among health professionals

- Report summarizing the activities of WP4, with, amongst others,
  - the improvement of knowledge on EMR CoE (Centre of Expertise)
  - the increase of awareness and training of General Practitioners and resident specialist doctors
  - the increase of the cooperation between the EMR partners
  - the translational aspects (clinical trials)
  - Kabuki as a model project for knowledge dissemination of a new therapy, and the exchange and training of health professionals from the CoE

**WP5** Patient involvement and public awareness

- Report including the PSB recommendations, on
  - the 3 National Plans for Rare Diseases
  - quality documents
  - cross-border healthcare
  - patient participation in medical research

**3**

### RECOMMENDATIONS AND SUPPORTING MATERIALS

#### 3 main recommendations:



##### 1. Holistic care:

Organising the care to take into account all the needs of people living with a RD



##### 2. Telemedicine:

Developing reimbursement of telemedicine for RDs



##### 3. European Solidarity:

Structuring the coordination and the solidarity for RDs at EU level

#### Supporting materials for raising awareness and provision of information

1. Factsheet for relatives and patients
2. Factsheet voor first line practitioners

**4**

### KEY MILESTONES



- **18/01/19 EMR Health Health Forum:** networking and policy event for Hospitals, health insurance funds, universities and patient organizations. The first recommendations on the pilot projects of EMRaDi were presented and discussed.



- **28/02/2019 EMR Rare Disease Day:** presentation of the first results and debate on how to improve the healthcare and quality of life of RD patients.



- **05/12/2019: EU Political Event:** presentation of our recommendations and factsheet which form the basis for future cooperation.



- **17/02/2020: Closure event:** signing of the declaration of intent for future cooperation and presentation of results and recommendations

#### PROJECT PARTNERS

LEAD PARTNER:

PARTNERS:

