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# CROSS BORDER HEALTH CARE & COOPERATION

**Matt Bolz-Johnson, EURORDIS**

Rare Diseases across the borders: Europe and  
the Euregio Meuse-Rhine

Maastricht, The Netherlands - 29 February 2019

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# Rare Disease Day

28.02 .2019

# Rare Disease Day 2019



90+ countries - New countries for 2019:  
Lesotho, Qatar, Namibia, Dominican Republic, Sri Lanka & Montenegro



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Theme: Bridging health and social care

EURORDIS  
RARE DISEASES EUROPE

# Cross-border Healthcare

# Cross-border Healthcare – Setting the Scene



**Common challenges** facing NHS systems are a **growing aging population & budgetary constraints**



**EU-level cooperation:** Council of the European Union in 2011 emphasised

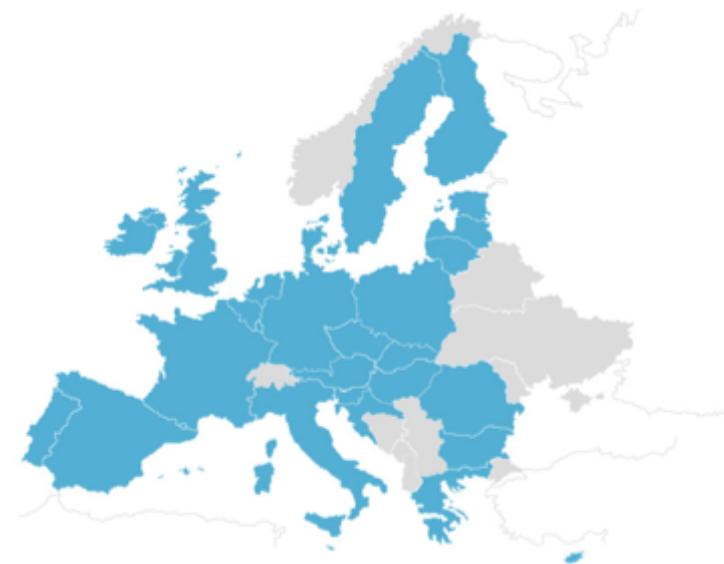
- “the need to join forces and enter into **more coordinated EU-level cooperation** in order to support Member States, when appropriate, in their efforts to ensure that their health systems meet future challenges”



**Cross-border regions**

- **Represent 40% of the territory of the EU; with 1 in 3 Europeans live in a border region.** There is a total of **37 cross border urban areas** in Europe
- EU MS need to:
  - **deepen cross-border healthcare cooperation**
  - stimulate a structural **exchange of best practices** among border regions
  - enhance the cohesion between border regions through the creation of an **EU cross-border mechanism**

# Cross-Border Healthcare Directive



Cross-Border Healthcare Directive was published in 9 March 2011 and was transposed into MS law in 25 October 2013.

To was build on 'case law' that acknowledged that [patients have, under specific conditions, the right to access healthcare in other MS](#) than their own.

The main purpose of the Directive is:

- [set of rights](#) to ensure the access of EU citizens to care abroad
- intention to [facilitate closer cooperation](#) in a number of areas of medicine and healthcare

# Regulation vs Directive

	E112/S2 FORM ROUTE	DIRECTIVE ROUTE
Sector	Public only	Public + Private
Eligible treatments	Treatments available under the other country's national health-insurance	Treatments available under your own country's health-insurance
Prior authorisation	Always Required	Not necessarily needed if treatment type is in the "basket of benefits"
Insurance may always refuse PA	True - unless un-due delay applies	True - unless un-due delay applies
Costs covered	Complete Funding - barring co-payment changes.	Reimbursement up to the amount had the treatment been carried out in your home country
Reimbursement of co-payment charges	Yes (under certain conditions)	No
Method of payment	Between MS, no up-front payment from patients required (funding-system)	Patients pay up-front and are reimbursed at a later time (reimbursement system)
Eligible countries	All EU & EEA countries + Switzerland	AL EU & EEA countries
Malpractice & Liability	Possible under country of treatment's laws and regulation	Possible under country of treatment's laws and regulations

7 Countries have free movement and choice (without prior-authorisation) – Czech Republic, Estonia, Finland, Lithuania, The Netherlands, Sweden and Norway

# Cross-border Activity

**After five years** since the Directive has been operational:

- Cross-border patient flows are **showing a stable pattern (no significant growth or reduction)**, mostly driven by geographical or cultural proximity

**Reasons for low patient mobility:**

- some Member States were quite **late implementing** the directive
- **citizens' awareness** about their general rights to reimbursement **is extremely low**
- Member States have **transposed the directive in ways that could be construed as limiting** cross-border healthcare

Figure 2: Requests for Reimbursement without prior authorisation

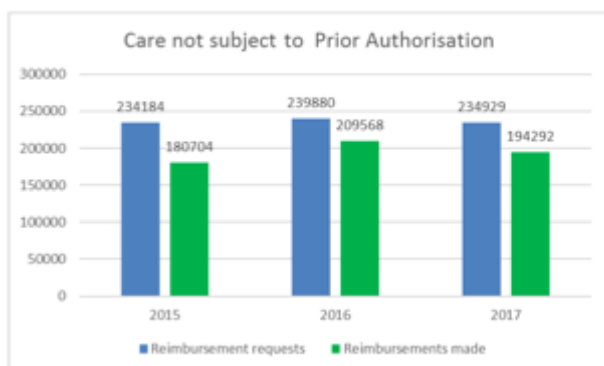
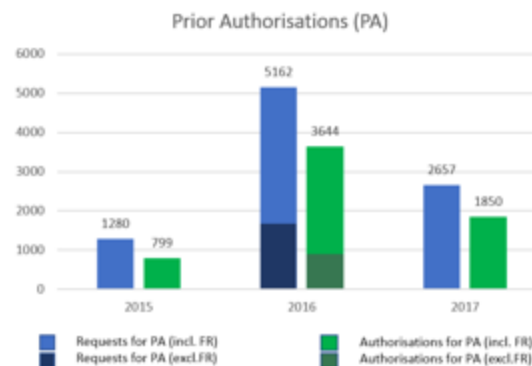


Figure 1: Prior Authorisation Requests and Authorisations





# €ross-border Spend



Majority of healthcare budgets is spent domestically as cross-border healthcare spend:

- Under the Directive - 0.004% of the EU-wide healthcare budget
- Under the Regulation - 0.1% of the EU-wide healthcare budget

## In summary:

- figures have been stable over the years, impact on national health budgets appears marginal
- this is true for all countries, no matter whether they introduced prior authorisation or not

**Footnote:** EU countries the average spent on healthcare is estimated to be €65,000,000 was spent across all EU MS on care with/without PA (2016).

10% of GDP is spent on healthcare in EU MS (Glance 24 report, OECD Health, 2017) with €15.3 trillion of EU GDP was spend on healthcare in 2017 (Eurostat25 reported)

# Patient Flows between Member States

Two significant trends in the direction of patient flows, with or without PA:

- 50% patient mobility may be driven by issues of proximity e.g.: neighbouring countries)
- 50% patients travelling throughout the EU to receive care e.g.: exercising their choice



## Main flows of patients with PA:

- France to Spain;
- Luxembourg to Germany
- Ireland to UK

## Main flows of patients without PA:

- France to Spain, Portugal and Belgium
- Denmark to Germany
- Poland to Czech Republic
- Norway to Spain.

# Barriers to Cross-border Healthcare

Lack of understanding of Patients Rights & logistical and administrative barriers can unintendedly affect the cross-border care for patients negatively.

Barriers:	Issue(s)
Systems of reimbursement:	<ul style="list-style-type: none"><li>• Lack of understand for on the differences between the Regulation and Directive</li><li>• 49% of EU national feel well informed about reimbursement within their country; and 17% in another country</li></ul>
Use of prior authorisation:	<ul style="list-style-type: none"><li>• Lack of information on the prior authorisation requests and time period required</li><li>• Lacking in-depth information on the NCPs websites - complaint procedures and settlement of disputes; and which treatments are reimbursed</li></ul>
Administrative requirements:	<ul style="list-style-type: none"><li>• 10% of Europeans have heard of their National Contact Points</li><li>• Lack of information on insight into what to do in the case of undue delay;</li></ul>
Charging of incoming patients:	<ul style="list-style-type: none"><li>• Fewer than 20% of citizens feel well informed about their cross-border healthcare rights. (Eurobarometer survey, 2015).</li></ul>

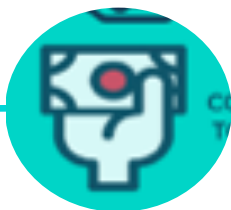
Source: EC Report to the European Parliament and the Council on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, 2018

# Types of Care You Wished To Report Difficulties About Accessing



	Belgium	The Netherlands	Germany
Visit to a Specialist	16.2%	37.0%	39.9%
Medicines & Medical Devices	58.1%	22.2%	28.6%
Social Care	17.6%	22.2%	10.2%
Hospitalisation	5.4%	0%	8.5%

# What Is Causing Difficulties In Access Care?



	Belgium	The Netherlands	Germany
Not well reimbursed	28.1%	21.2	12.8%
Could not afford to pay in advance	11.5	6.1	8.1%
I have to wait too long	18.7	15.2	22.5%
Didn't know any specialist	10.8	15.2	21.1%
Too far away or no means of transportation	8.6	3.0	11.2%

# Cross-border Cooperation

## ERNs



- 24 European Reference Networks
- EU flagship initiative
- Pooling of knowledge
- Launch of ERNs marked a major change in the delivery of healthcare cross-border to EU citizens

## Rare Diseases



- Increase public awareness of rare disease
- Increase funding for R&D
- European Joint Programme on Rare Diseases

## HTA



- Health Technology Assessments
- EUnetHTA network for HTA across EU
- Legislative proposal on Health Technology Assessments by the EC

## eHealth



- eHEALTH
- ePrescription and Discharge Summary
- Challenges ICT adoption & specific to complexity, governance, local conditions and stakeholder engagement



# EU Voluntary Cooperation

# ERN Spearhead EU Expertise



Networks harness the collective knowledge and experience of experts, focusing on a common goal to drive **improve access to diagnosis and treatment** by enabling expertise, not the patient:

- Connect expert, anchored into national health systems
- Creating a critical mass of cases and data
- Inclusive, not exclusive, multi-professional, not single professional
- Common language, common platform enabling mobility of expertise
- Collaborative spirit, trust and sharing with a common goal
- Drive research and new therapies
- Increase patient outcomes and survival



# EUREGIO MEUSE-RHINE Region – ERN HCPs

Already hospitals are collaborating in the EUREGIO MEUSE-RHINE Region – case conferences in the region!

## University Hospital Leuven:

- Endo-ERN
  - ERKNet
  - ERN LUNG
  - ERN EURACAN
  - ERN EpiCARE
  - ERN EuroBloodNet
  - ERN eUROGEN
  - ERN EURO-NMD
  - ERN GENTURIS
- ERN GUARD-HEART
  - ERN ITHACA
  - MetabERN
  - ERN PaedCan
  - ERN RARE-LIVER
  - ERN RITA
  - ERN Skin
  - ERNICA
  - ERN-RND
  - VASCERN

## University Hospital Liège:

- Endo-ERN
- ERN EURACAN
- ERN EuroBloodNet
- ERN eUROGEN
- ERN GENTURIS
- MetabERN

## Maastricht University Medical Center+ :

- Endo-ERN
- ERN EURACAN
- ERN EURO-NMD
- ERN ITHACA
- MetabERN
- ERN SKIN

## Uniklinik RWTH Aachen:

- Endo-ERN-ERN
- RareERN RARE-LIVER



# eCounselling - Expertise travels, not the Patient



Patients

National Healthcare  
Provider

RD Specific ERN

- **Virtual healthcare:** specialist advice
- **Knowledge generation:** sharing experience and expertise, research and innovation
- **Knowledge dissemination:** clinical guidelines, healthcare pathways, education and training



End of 2019, patients benefit from the ERN via the CPMS:  
**404 panels opened & 109 panels closed**

# Cross-border Training & Education

- **Maltese EU Presidency** - 'Structured cooperation for training and service delivery in highly specialised health services through European Reference Networks' La Valletta, 02.03.17
- ERNs will be re-evaluated by the European Commission end of first 5 years. It will be **important to demonstrate the added value that ERNs bring**, for example, in training / education - 70% HCP Members from EU5 with **added value to the other EU23**



- **Education and training are a critical Network activities** to share expertise and knowledge within the ERNs and between EU countries and drive improvements to quality and patient
- ERNs **funding opportunities** to support and facilitate training and education activities:
  - EC C4T on ERN Training of Affiliated Partners (Health Programme, 2018)
  - H2020 Funding on research in innovative training under ERNs for super-specialisation

[https://www.eu2017.mt/Documents/Programmes/PB20\\_OBS\\_POLICY\\_BRIEF.pdf](https://www.eu2017.mt/Documents/Programmes/PB20_OBS_POLICY_BRIEF.pdf)

# Summary



- **Cross-border patient flows** are showing:
  - a stable pattern, mostly driven by geographical or cultural proximity,
  - not resulted in a major budgetary impact.
- **Implementation of CBHC Administration**
  - Reimbursement procedures need to be simplified
  - Information-campaign on NCP's and on patients' rights
  - National Contract Points should be invested in and developed to increase accessible & visibility
- **European Reference Networks** are seen as the EU flag-ship initiative:
  - Further development and financing of the ERNs
  - Scaling the ERN model up and call for a fresh call for new ERNs
  - Need to establishing clear, transparent rules for patient referral between NHS & ERNs.

# Vastelaovend het is!



Es ist Karnveal! Für Aachen, alaaf, alaaf, alaaf