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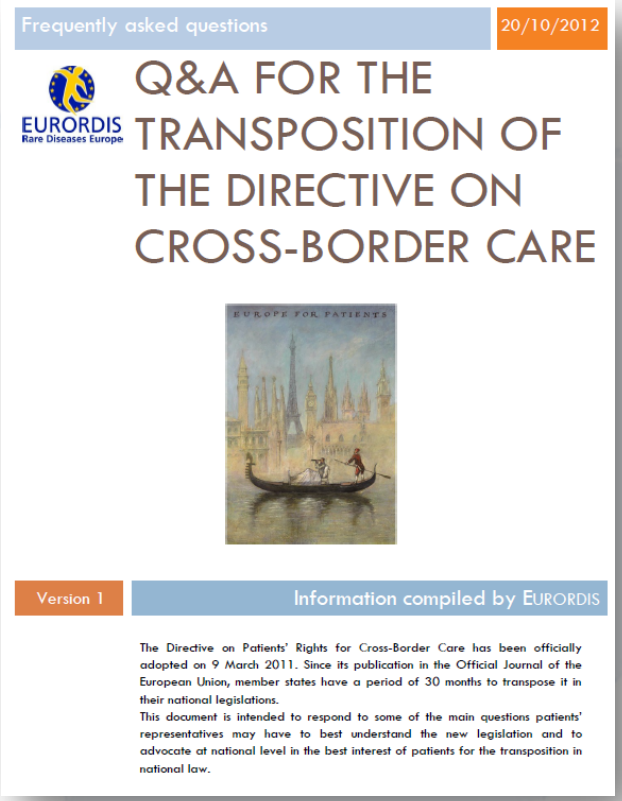
Rare Diseases Europe

Patients' rights to cross-border care: back to the European Court of Justice?

François Houÿez, Director of Treatment Information and Access

Interest Group "European Patients' Rights & Cross-Border Healthcare", 1 March 2017, European Parliament,

2012: Eurordis advised its members



Frequently asked questions 20/10/2012

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Q&A FOR THE TRANSPOSITION OF THE DIRECTIVE ON CROSS-BORDER CARE

Version 1 Information compiled by EURORDIS

The Directive on Patients' Rights for Cross-Border Care has been officially adopted on 9 March 2011. Since its publication in the Official Journal of the European Union, member states have a period of 30 months to transpose it in their national legislations.
This document is intended to respond to some of the main questions patients' representatives may have to best understand the new legislation and to advocate at national level in the best interest of patients for the transposition in national law.

- ***Can I seek healthcare abroad if the treatment is not available in my country? C.U.P?***
- ***Do we pay full costs in advance, and be reimbursed at a later stage?***
- ***When can prior- authorisation be refused?***
- ***Is there a different price, one for their fellow citizens and another one for foreigners?***
- ***Can we ask for travel and accommodation expenses to be also reimbursed?***
- ***Where can we find information on care provided in other Member States?***
- ***In case something goes wrong, who is liable?***
- ***Can all cost be reimbursed, including travel?***
- ***Can Member States limit cross-border care?***
- ***Etc.***

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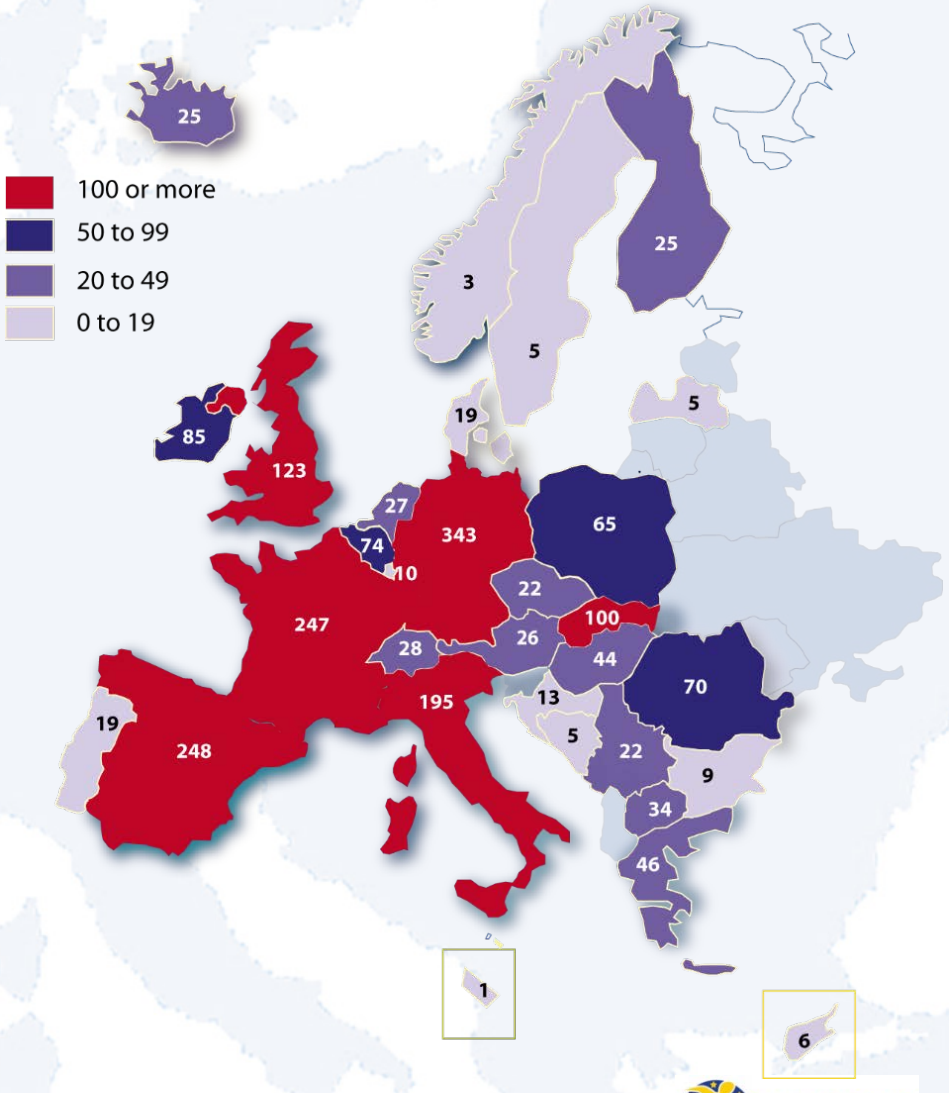
The Access Campaign Survey

- Difficulties patients with rare diseases have accessing care
- Data collection May 2014 to September 2016
- 1,943 valid responses
  - from 66 countries, of which 31 in Europe



CAMPAIGN FOR ACCESS To MEDICINES FOR PEOPLE WITH RARE DISEASES

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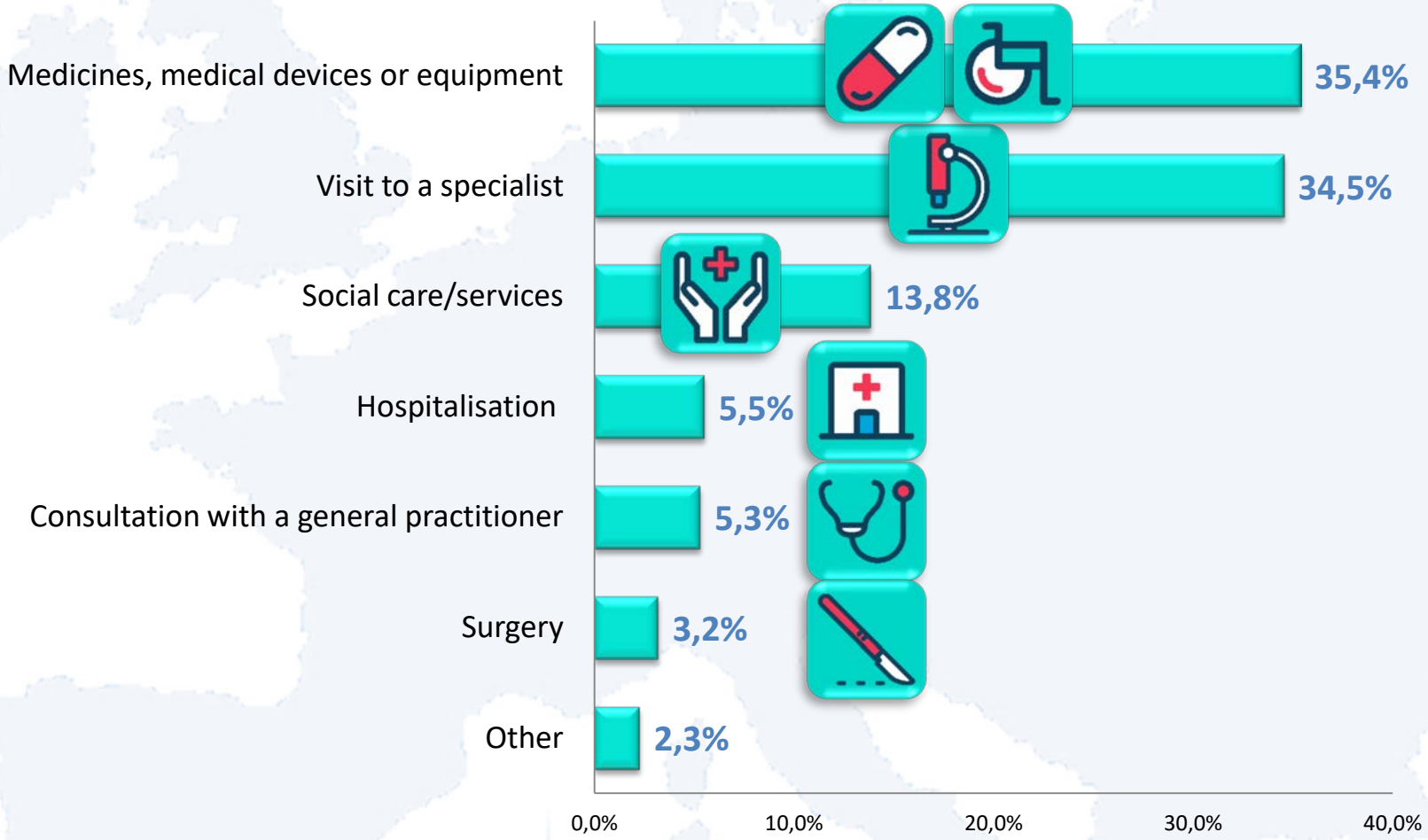
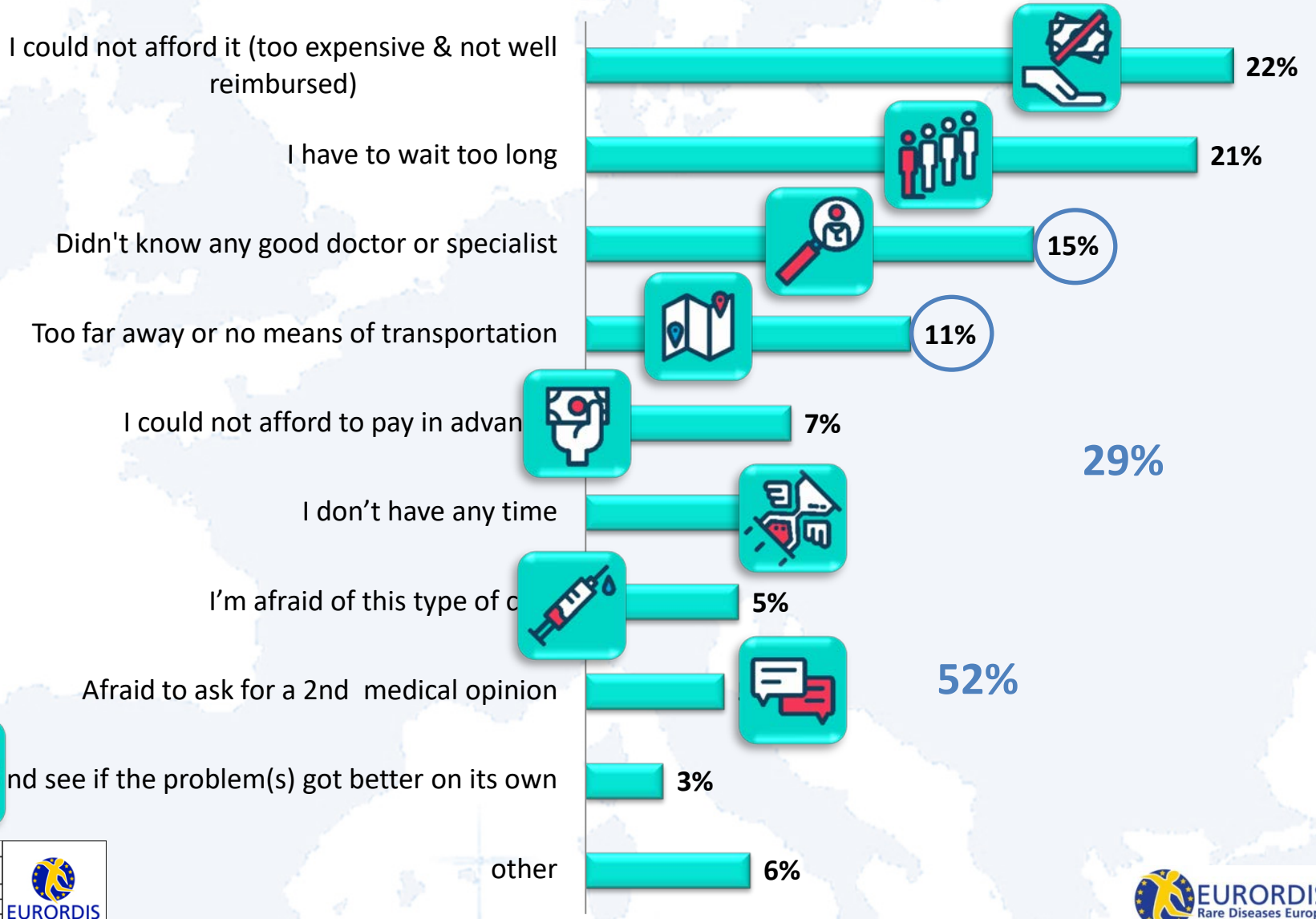
Question 1 : Please indicate for which type of care you wish to report difficulties about ? (1,943 responses, Europe)



Q5 : Which type of issues are causing you difficulties ? (Europe, several responses possible)



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06/03/2017

Since the adoption of the Directive (1)

France → Cyprus 2013

Patient with Tarlov Kyst	Cyprus	Response from health insurance	Lessons
High grade pain, sciatic neuralgia, pudendal neuralgia Consulted 5 specialised surgeons - 3 didn't know how to treat - 2 knew about the surgery but not enough experience	An experienced US surgeon with 700+ patients often operates in Cyprus 09/2013: Patient asked for prior authorisation to go to Cyprus as: - This type of surgery is in the basket of care in France - No equivalent treatment can be proposed 10/2013: surgery in Cyprus	25/11/2013 Negative as: 1. This type of surgery is done but not « recognised », therefore not coded, and if not coded, it cannot be authorised 2. Technically the surgery can be made in France (equipment exists) → Appeal to Commission	02/2014: 8,000€ reimbursed by Sécurité Social, and 24,000€ by private insurance (travel costs excluded). Typical case of undue delays and complex procedures to dissuade patients Not a issue about the Right, but about Access to Right

Since the adoption of the Directive (2)

France → United Kingdom, Spain, Netherlands 2013

Student with PNH	Response form French health insurance	In fact
Paroxysmal Haemoglobinuria Preparing for an Erasmus In London, Madrid or Amsterdam Treatment needs 2 injections/month and costs 18,000€ a month Hospital in London agreed to treat but requested French health insurance to pre-pay	On the contrary the patient should ask the hospital in the country of treatment to pre-pay	The health insurance to which the patient is affiliated should pay directly to the dispensing hospital, Which requires full transparency on the cost of care, including pharmaceuticals If care is more expensive in country of treatment, the patient pays the difference and asks for reimbursement to his health insurance.

Since the adoption of the Directive (3)

United Kingdom → France 2016

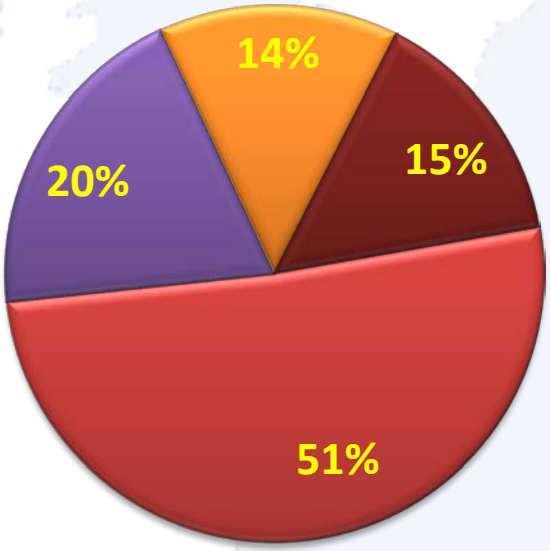
Boy with Leprechaunism	Response form commissioning group	Problem
Treated with mecasermin Major skin reaction to treatment Disease specialist in France Funding application to local commissioning group NHS	Outpatient consultation at Paris Hospital, limit €1800/year Cerat de Gallien (cold cream), 4 pots/month, limit € 3000/year Spa treatment, one visit, limit €1300/year	1. The patient needs 12-16 pots of cold cream per month, more than 4 2. Decision for 1 year To be renewed, conditioned to **evidence of clinical improvement**, using objective measures, from baseline

Cross-border care and telemedicine?
Ireland → Belgium

- Patient with Lyme disease
  - For 2 and half years: unable to get advise from GP's on what was causing symptoms
  - Had to travel to Belgium to see specialist, got the proper tests, got a diagnosis
  - Then came home and was refused proposed treatment by foreign specialist by Infectious Disease specialist
  - Had to travel to Brussels to stay for 3 months for treatment. With great expense and difficult in organising when extremely ill and disabled

Where do you get your medicines?

If not from your usual care centre (n= 274 / 1,350 responses), where do you get it from?



- I go to a different hospital or pharmacy
- I go to a different town
- I go to a different region
- I go to a different country **47 responses (3.4%)**

Survey on Treatment information in rare diseases 2016, EURORDIS DITA task force
Field work 15 February- 31 May 2016. 1,350 responses
Funded by an operating grant from the public health programme DG Sante

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Possible measures

European Reference Networks

- Legally in place: 1 March 2017!
- The expertise should travel, more than the patients
- Relations between ERN and local healthcare professionals?

Telemedicine

- Can only work if healthcare professionals are paid for the time spent

Information campaigns on patients' rights

- But political obstruction to inform citizens about their rights to cross-border care
- A role for NGOs, patients' groups, help lines, social networks…

Back to ECJ?

- Procedures still complex, often arbitrary, unclear and lengthy appeal procedure

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- Thank you!

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EURORDIS- Celebrates the launch of 24 European Reference Networks for Rare Diseases

European Reference Networks are:

- **Patient-centred**, involving patients from the start and as equal partners in all ERNs
- **Optimal framework** for multisystem rare diseases, enables that every patient with a rare disease to have a home under an ERN, to leave no one behind
- **Anchored into national health systems**, connecting patients, clinicians and researchers
- Vehicle that will pave the way for **faster diagnosis and access to expert care**, by making experts visible and expertise travelling, not the patient

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ERNs are a game changer for Rare Diseases: There will be “before” and “after”

ERNs is already a ‘game changer’ in healthcare:

- **European wide collaboration** with nearly 1000 HCP from 26 Member States in 24 ERNs
- **Create a critical mass of patients and data**, push the pace of research and clinical practice
- **Magnetise patients needs to the right expert**, leading to faster diagnosis and treatment
- **Transparency on patient health outcomes from care received** as a driver for clinical excellence
- **Connect and implement existing knowledge and experience** of leading clinicians, researchers and patients
- **Generate new knowledge**

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