Patients’ Needs and Expectations: Access to Health Services

The EurordisCare 3 Study

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Purpose of the EurordisCare Survey

• To describe and compare the experiences and expectations of patients or patients’ relatives regarding access to health services in Europe

• To make the patient voice heard at a time when several European countries are reorganising health services for rare diseases

• To make comparisons:
  ▪ between diseases
  ▪ between countries
EurordisCare 3 in some figures

- One common questionnaire
- Adapted
  - to 16 RD (the top-8 medical services for each disease)
  - to 23 countries (national family incomes values)
- Translated into 15 languages
- 20 022 copies provided to 130 committed patients’ organisations, sended to its members
- 5 995 (30%) responses from patients received at Eurordis
- 1 020 000 data recorded
Presentation of Results

For methodological reasons, averages were calculated for countries with more than:

- 60 responses
- 4 diseases

Wherever “overall” values are indicated, this represents responses from all countries.
Patients’ experiences: 3 sets of observations

1. Rejection

2. The complexity of the diseases, requires
   - Better coordination amongst health professionals
   - A multidisciplinary approach
   - A comprehensive approach including facilitating access to specific social services.

3. In some countries the difficulties in accessing services are so serious that they translate into lack of access however in other countries patients are able to overcome them.
First set of observations – (1)

Health professionals are unfamiliar with rare disease patients and often reject them because they are ‘unusual’ in terms of:

- Physical appearance of patient
- Disease-related behaviour
- Communication difficulties

**Need to:**

Raise awareness of the public and health care professionals
Overall rejection rate by health professionals

Overall: 18%

BELGIUM (255)
SPAIN (499)
ROMANIA (60)
HUNGARY (408)
FRANCE (1574)
SWEDEN (497)
NETHERLANDS (396)
UNITED KINGDOM (340)
DENMARK (277)
FINLAND (146)
ITALY (691)
SWITZERLAND (60)
GERMANY (451)

Overall, 18% of patients were rejected by health professionals.
Causes of rejection linked to the patients

6% of responders felt rejected for personal reasons, with a wide variability in frequency between countries.

Overall: 6%

reasons for rejection (several reasons possible for same patient)

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Causes of rejection linked to the patients

Overall: 6%

- Huntington disease (207)
- Tuberous sclerosis (383)
- Ehlers Danlos syndrome (822)
- Williams syndrome (390)
- 11Q deletion syndrome (40)
- Ataxia (570)
- Prader Willi syndrome (371)
- Marfan syndrome (419)
- Fragile X syndrome (257)
- Myasthenia (647)
- Osteogenesis imperfecta (421)
- Pulmonary arterial hypertension (456)
- Epidermolysis bullosa (249)
- Aniridia (145)
- Cystic fibrosis (539)
- Alternating Hemiplegia (79)

A wide variability in rejection according to the diseases

Need to educate regarding being ‘different’ or ‘special’

Patients experiencing a rejection (several reasons possible for same patient)
Health professionals are unfamiliar with rare diseases and therefore often reject the patient:

– because of the complexity of their disease
– because of their rarity and extreme rarity

Need to:

Train physicians
Rejection linked to the disease, by country

Overall: 14%

- BELGIUM (85)
- ROMANIA (15)
- SPAIN (131)
- SWEDEN (89)
- HUNGARY (86)
- FRANCE (297)
- DENMARK (40)
- FINLAND (20)
- NETHERLANDS (66)
- ITALY (95)
- UNITED KINGDOM (53)
- SWITZERLAND (8)
- GERMANY (32)

In most cases, rejection was attributed to a reluctance of the professional due to the complexity of the disease and lack of knowledge on rare diseases by professionals.
Rejection linked to the disease, by disease

Overall: 14%

- Alternating Hemiplegia (79)
- 11Q deletion syndrome (40)
- Tuberous sclerosis (383)
- Osteogenesis imperfecta (421)
- Myasthenia (647)
- Marfan syndrome (419)
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In most cases the rejection was attributed to a reluctance of the professional towards the complexity of the disease.

Need to educate regarding rarity, uniqueness and complexity.

percentage of patients experiencing rejection by health professionals
Rare diseases are complex, frequently multi-organ and multi-faceted

Need to:

- communicate and coordinate amongst health professionals
- have a multidisciplinary approach
Rare diseases require complex care

On average, rare disease patients needed 9 different types of care or medical services over a period of 2 years.

Care 25%
Consultations 42%
Tests 33%

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Needs of RD patients are complex

Medical service requirements for patients with rare diseases

Survey responders reported an individual need for more than 9 different medical services (over the last 2 years) including:

- 4.0 different types of consultations
- 3.1 different types of tests
- 2.3 different types of care
Diversity in medical needs of RD patients

Overall, the diversity in services used by each patient is:

- 4.0 different (types of) consultations
- 3.1 different tests
- 2.3 different care

The proportion of each category varies slightly according to the disease.

Number of different medical services used per patient over the last 2 years

A useful tool to prioritise centres of expertise
95% of patients say that medical information sharing and coordination between all professionals who care for her/him in the specialised centre is useful or essential.
Third set of observations

Rare disease patients are experiencing a real issue of lack of access to essential medical services.
Difficult access to medical services

Difficult or Impossible, overall: 27%

In more than ¼ of situations access to medical services was considered difficult or impossible

* “situation”: one essential medical service expected by one patient
Lack of access to essential medical services needed

Of the 11% with no access, 69% of these were due to lack of referral.

- Personal cost: 28%
- Distance: 33%
- Waiting time: 41%
- Unavailability: 52%
- Lack of referral: 69%

% of services not accessed
Reasons for lack of access to medical services, excluding travel

The most frequent reason for the lack of access to expected essential medical services is a lack of referral, followed by unavailability and waiting time.
Reasons for lack of access to medical services, related to travel

The impact of having to travel, and the hurdles encountered when travelling to the medical service, varies widely and depends on the country.
Need for co-ordination

Lack of Referral
is the main reason for
lack of access to medical services
therefore

Need for:

- Better co-ordination amongst health professionals
- Education of professionals
- Information tools, to guide and orientate
Fourth set of observations

Rare disease patients need an integrated medical and social approach
Rare disease patients need
- More and easier access
- Better quality of social services

Key findings:
- needs vary a lot according to the disease
- access varies a lot according to the country
- overall for 32% of patients access was impossible or difficult
- dissatisfaction varies a lot according to the country
- overall, 52% of patients had no access or were unsatisfied
The need for social assistance varies according to the disease

Overall: 29%

Over the last 12 months, almost a third of patients responded that they needed to meet with a social worker.
32% of patients said it was difficult or impossible to access social assistance.
Access to social assistance was difficult to impossible for one patient out of three.
Satisfaction with social assistance

In more than half the cases, patients were unsatisfied with the social assistance offered.

Lack of access or Unsatisfied, overall: 52%

- HUNGARY
- DENMARK
- UNITED KINGDOM
- GERMANY
- SWEDEN
- SWITZERLAND
- SPAIN
- NETHERLANDS
- ITALY
- FINLAND
- FRANCE
- BELGIUM
- ROMANIA

percentage of patients satisfied by social assistance

0% 25% 50% 75% 100%
Even when obtained, in almost half the situations, patients were unsatisfied with the social assistance offered.
Conclusions

In order to address the major issues of:

• Rejection by health professionals
• Lack of access to services: (medical and/or social)
• Lack of satisfaction with social services
• Lack of coordination and communication between health professionals
• Variability of access between different countries
Conclusions

Rare disease patients expect Centres of Expertise:

• where patients do not feel rejected and meet health professionals who are knowledgeable about their disease

• that are multi-disciplinary

• that integrate medical and social needs

• where health professionals coordinate and communicate with each other

• where health professionals refer to other professionals in the medical and social fields
Conclusions

Given that the degree and types of difficulties in accessing health and social services vary a great deal from country to country:

There is reason to believe that:

• solutions exist and can be transposed from one country to another

• identification and benchmarking of best approaches (disease/country) as well as dissemination and exchange of these approaches are the right ways to promote these solutions

• a common ground of patient needs, experience and expectations provide a solid base for a common set of claims and propositions to improve access and satisfaction across Europe.

• raising awareness of the public, policy makers and professionals as well as education of professionals is essential
Your input for the Declaration!

Please fill out the consultation on the Draft Declaration and return to the Eurordis staff members before lunch

So that it can be analysed before Workshop 4

Thank you for indicating the disease and the country you represent