



Patients' Needs and Expectations: Access to Health Services

The EurordisCare 3 Study – Final Key Findings



Patients'
Survey

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Content

- **Introduction**
 - Purpose of survey
 - Conduct of survey
 - Presentation of results
- **Patients' experience: 4 sets of observations**
 - Rejection due to unusualness and complexity
 - Need for multidisciplinary and coordinated approach
 - Lack of access to essential medical services
 - Need for comprehensive approach integrating social services
- **Conclusions**

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

- Marfan syndrome
- Fragile X syndrome
- One common questionnaire
 - Williams syndrome
- Adapted
 - Ehlers-Danlos syndrome
 - to 16 RD (the top 8 medical services for €)
 - to 23 countries (national family incomes)
 - Prader-Willi syndrome
 - Epidermolysis bullosa
- Translated into 15 languages
 - Tuberosclerosis
- 20 022 copies provided to 130 committees
 - Myasthenia
 - Osteogenesis imperfecta
- 5 995 (30%) responses from patients recorded
 - Huntington disease
- 1 020 000 data recorded
 - Ataxias
 - Aniridia
 - Pulmonary arterial hypertension
 - Chromosome 11q disorders
 - Alternating hemiplegia

- Austria,
- Belgium,
- Croatia,
- Cyprus,
- Czech Republic,
- Denmark,
- Finland,
- France,
- Germany,
- Greece,
- Hungary,
- Ireland,
- Italy,
- Luxembourg,
- Malta,
- Netherlands,
- Norway,
- Romania,
- Slovakia,
- Spain,
- Sweden,
- Switzerland,
- United Kingdom

C
D
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Hungarian,
Italian,
Norwegian,
Romanian,
Slovak,
Spanish,
Swedish



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 cumulated from all countries

First set of observations – (1)

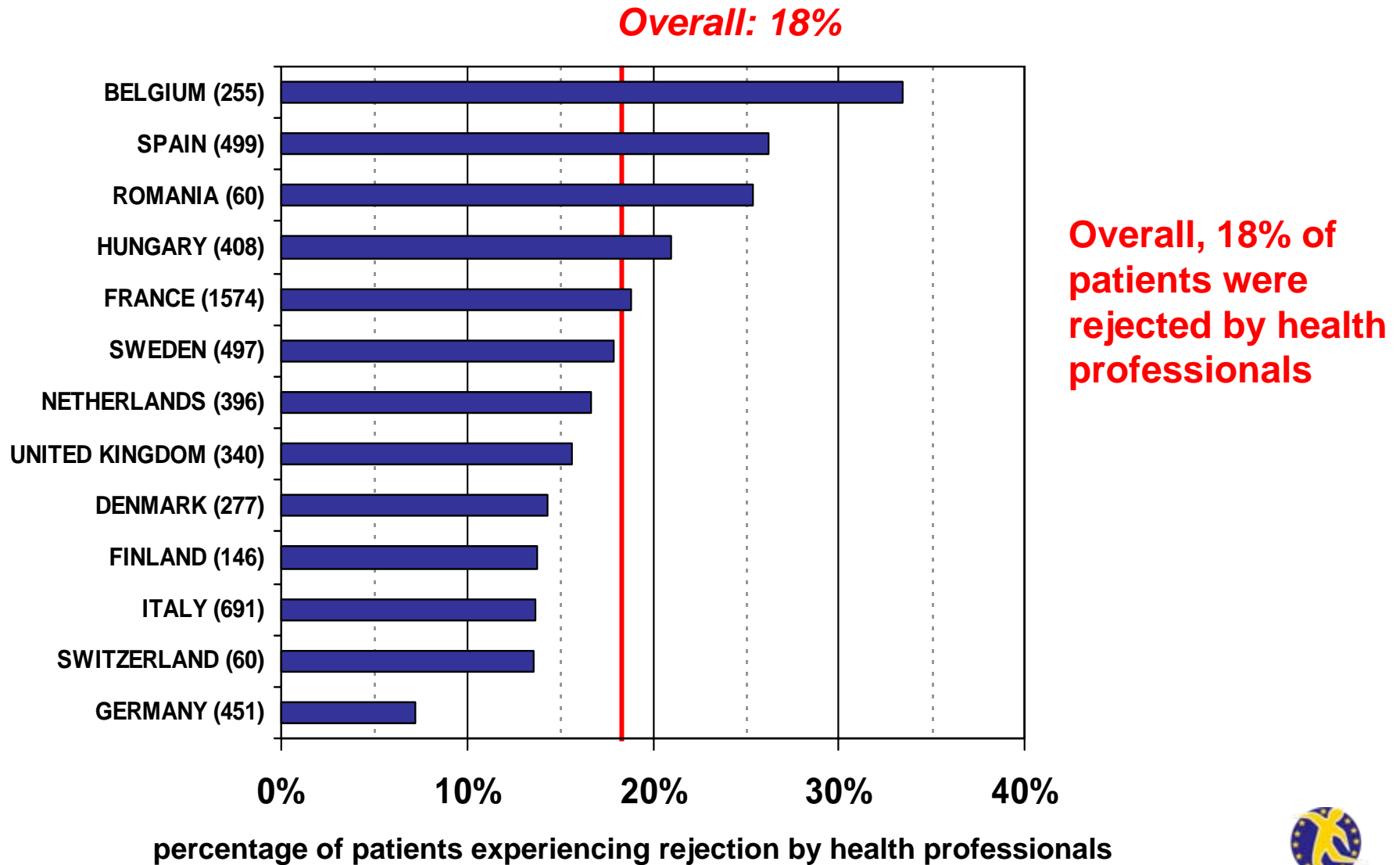
Health professionals are unfamiliar with rare disease patients and often **reject** them because they are **'unusual'** in terms of:

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

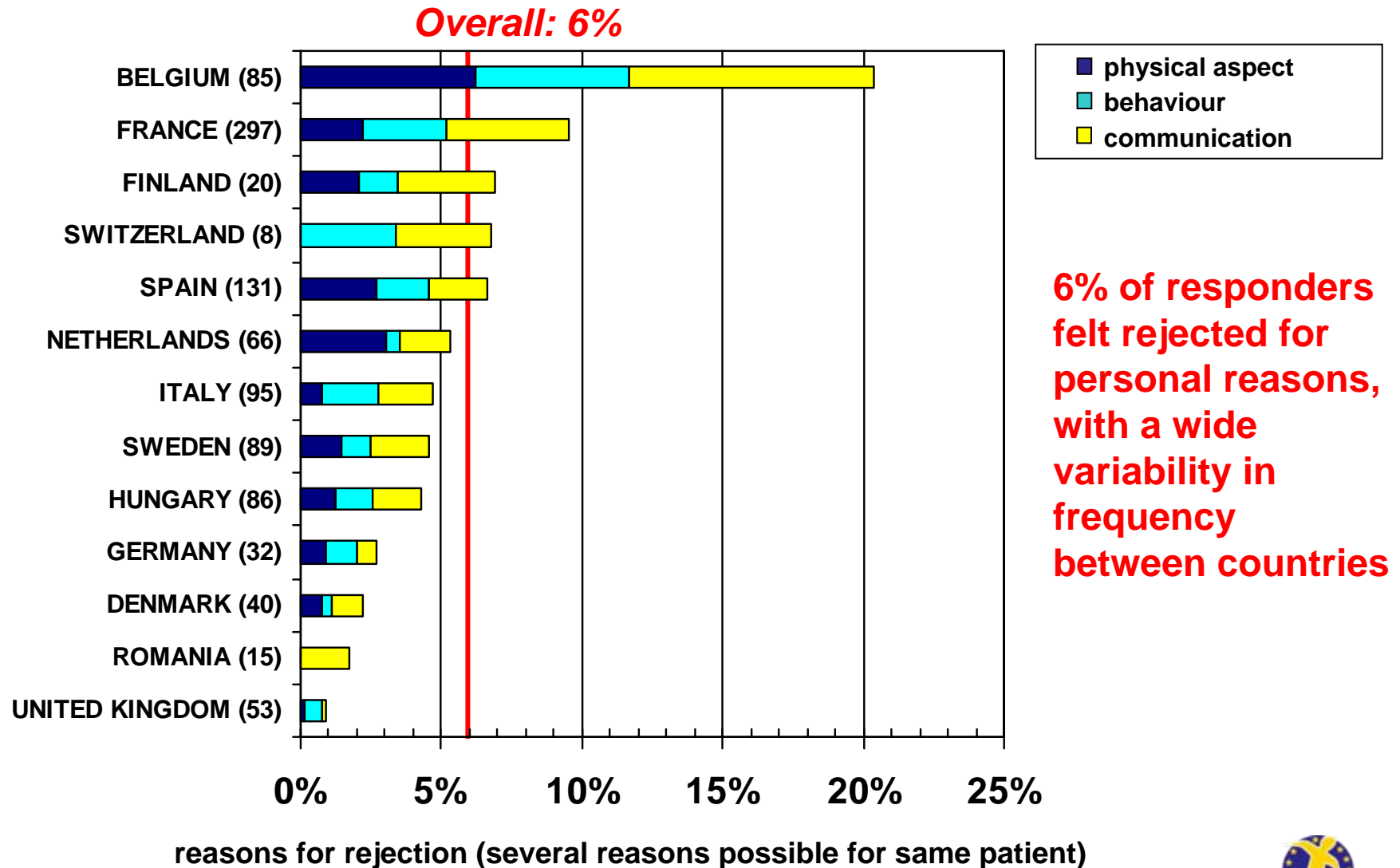
Need to:

➡ **Raise awareness of the public and health care professionals**

Overall rejection rate by health professionals

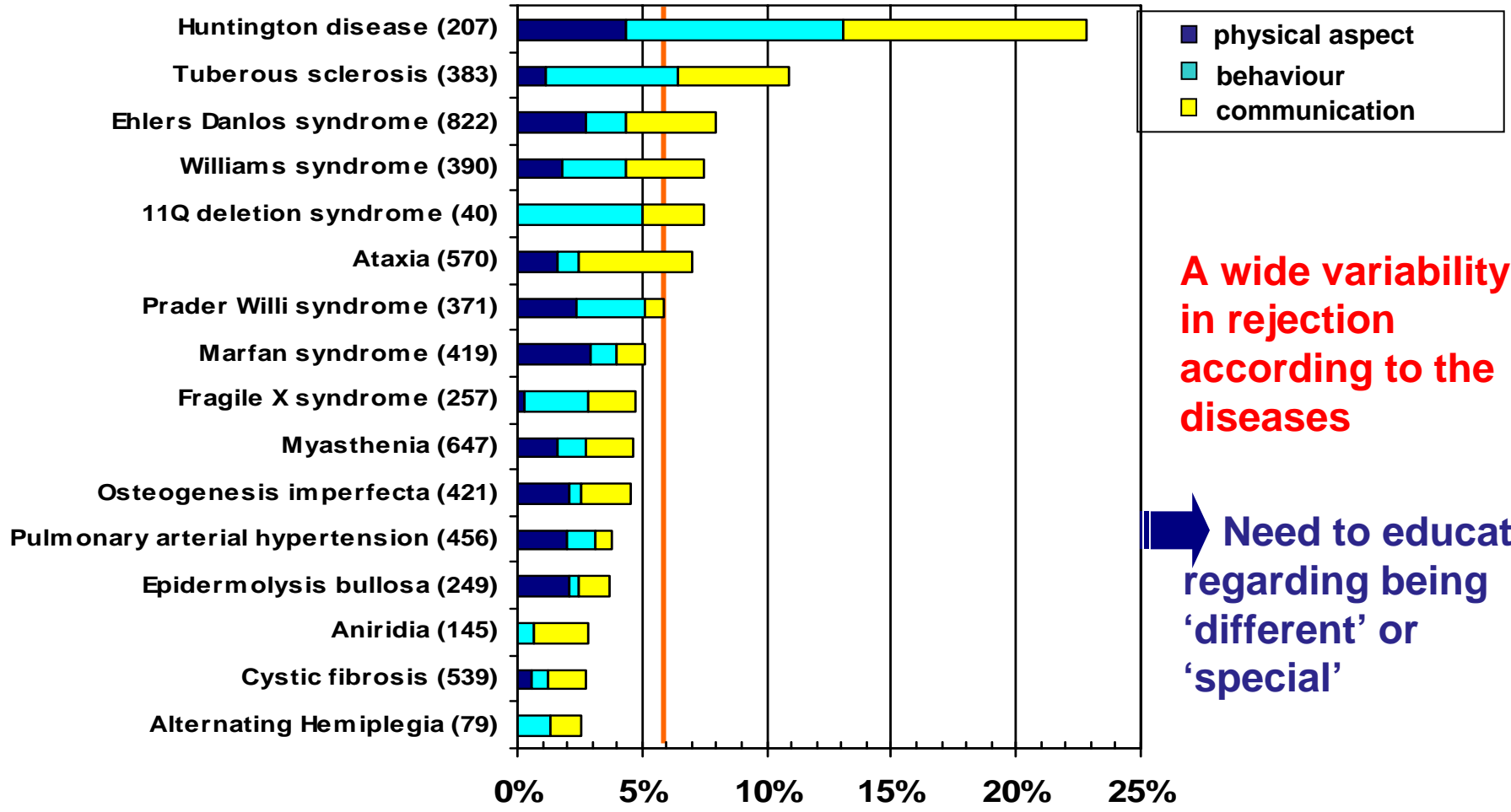


Causes of rejection linked to the patients



Causes of rejection linked to the patients

Overall: 6%



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)

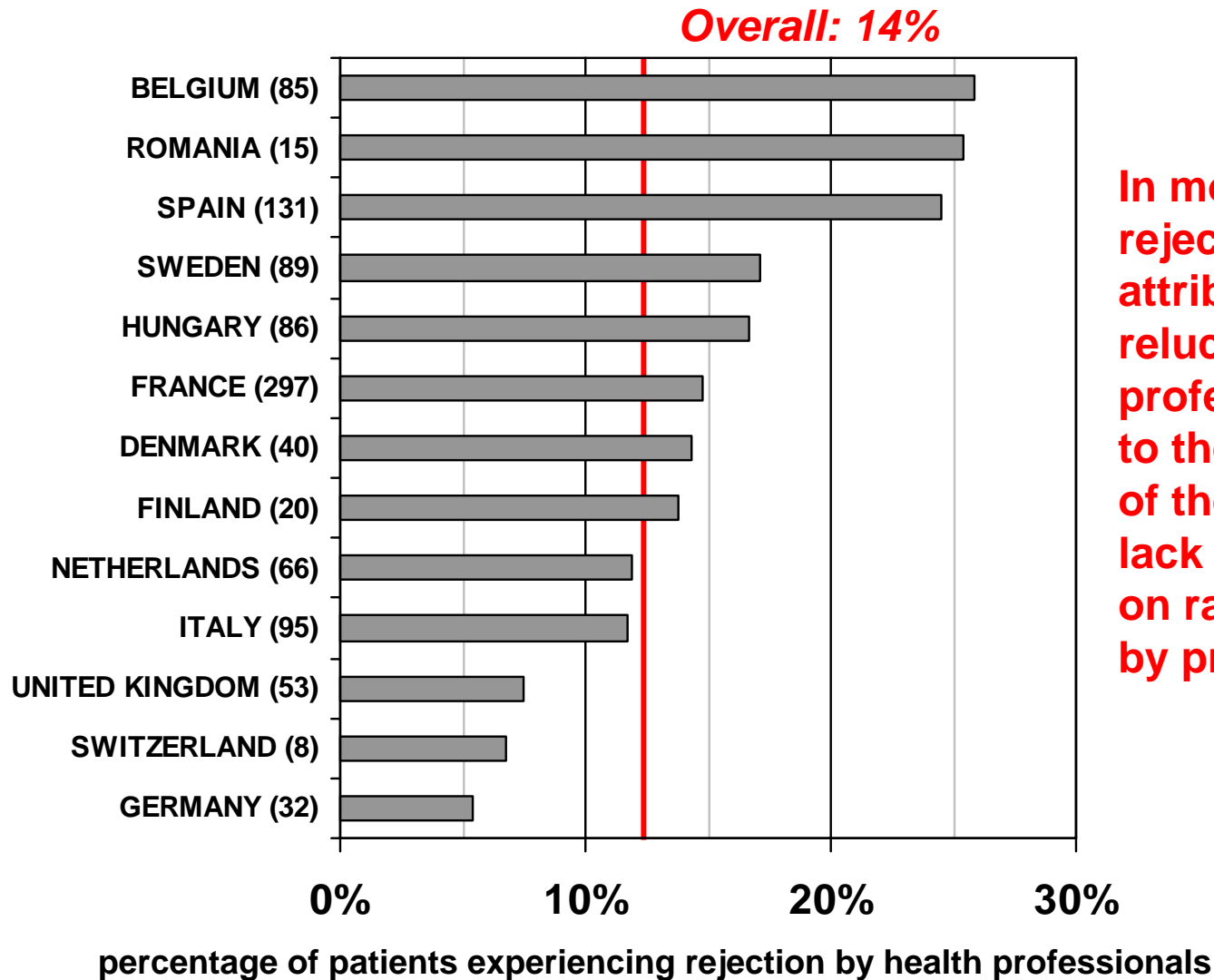
First set of observations – (2)

- 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**

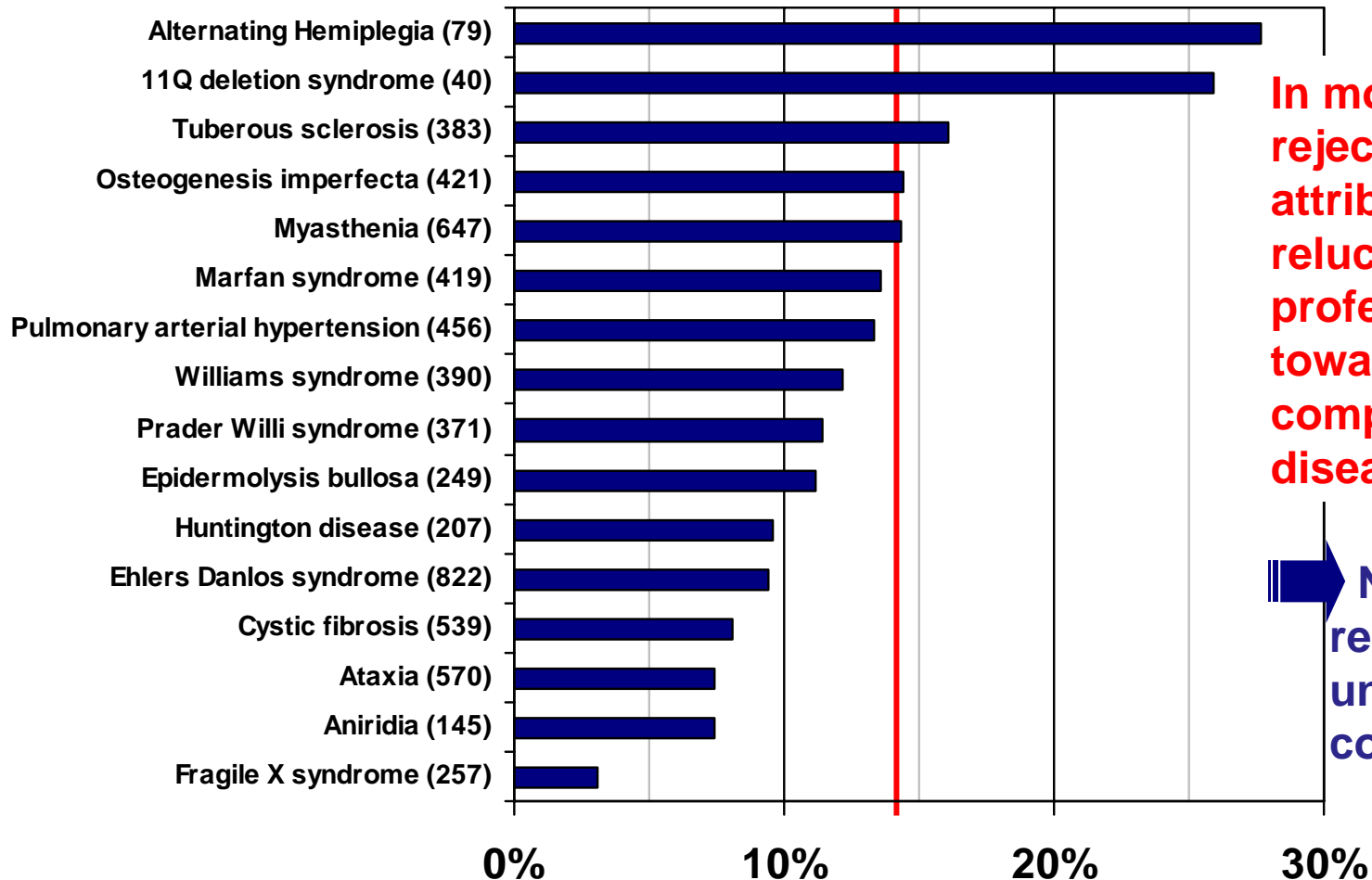
Rejection linked to the disease, by country



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 %



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

Second set of observations

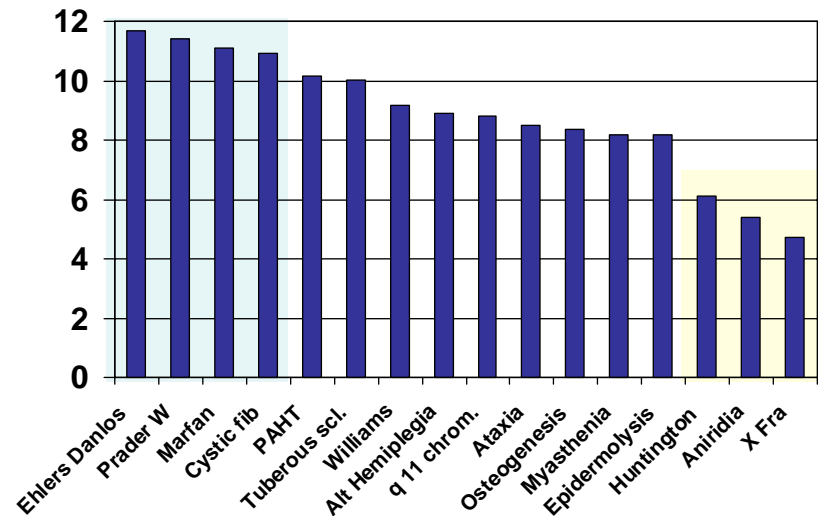
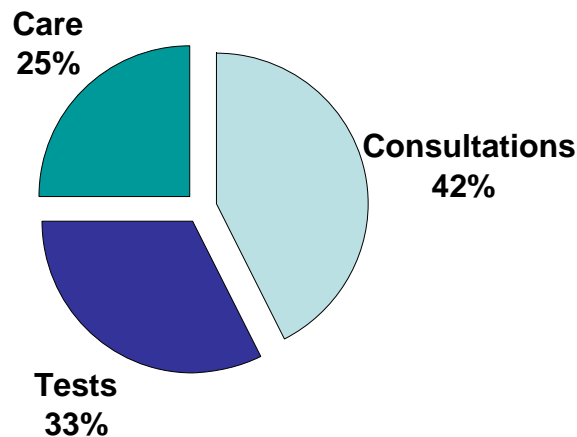
**Rare diseases are complex,
frequently multi-organ and
multi-faceted**

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



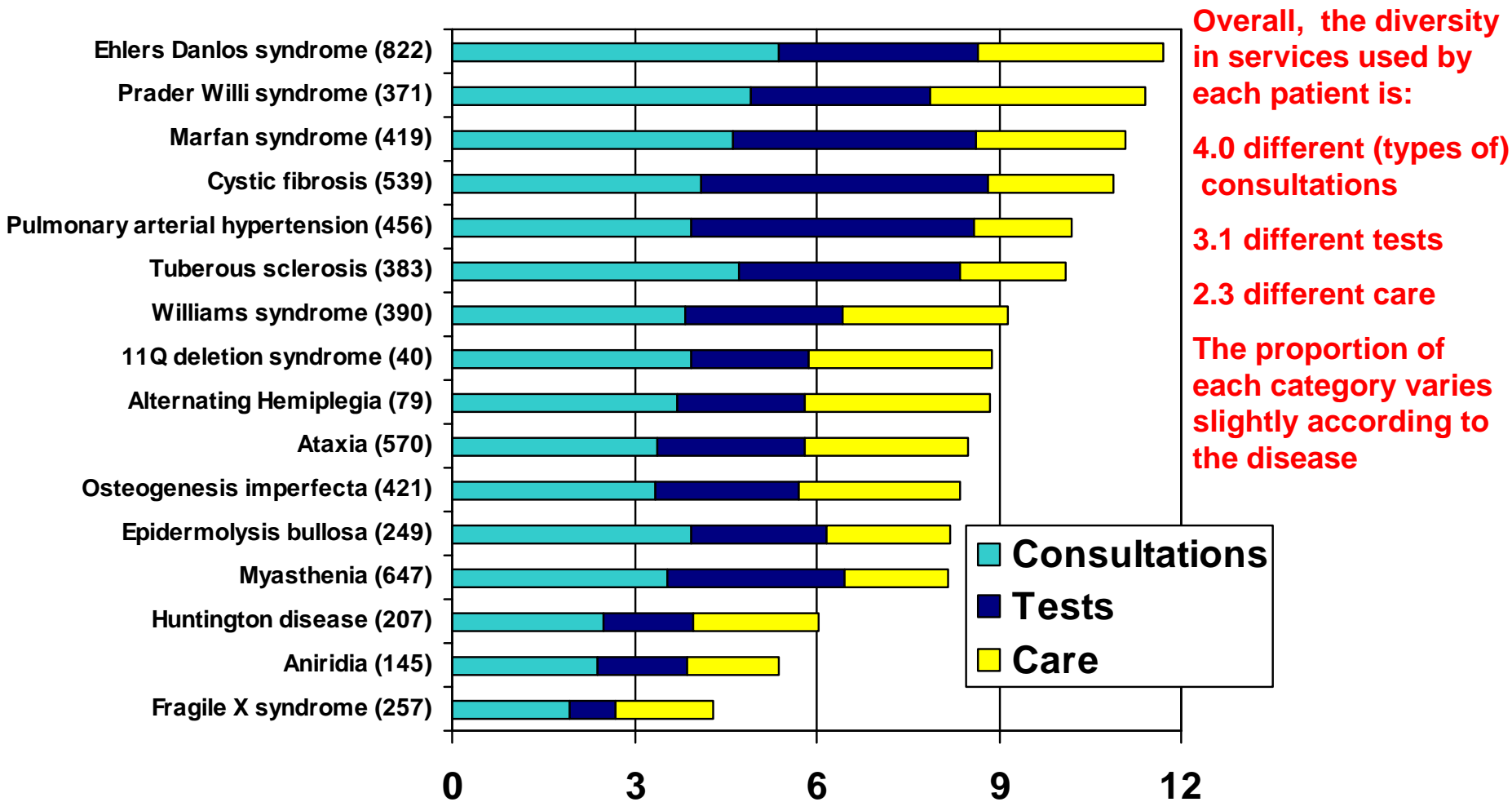
Needs of RD patients are complex

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

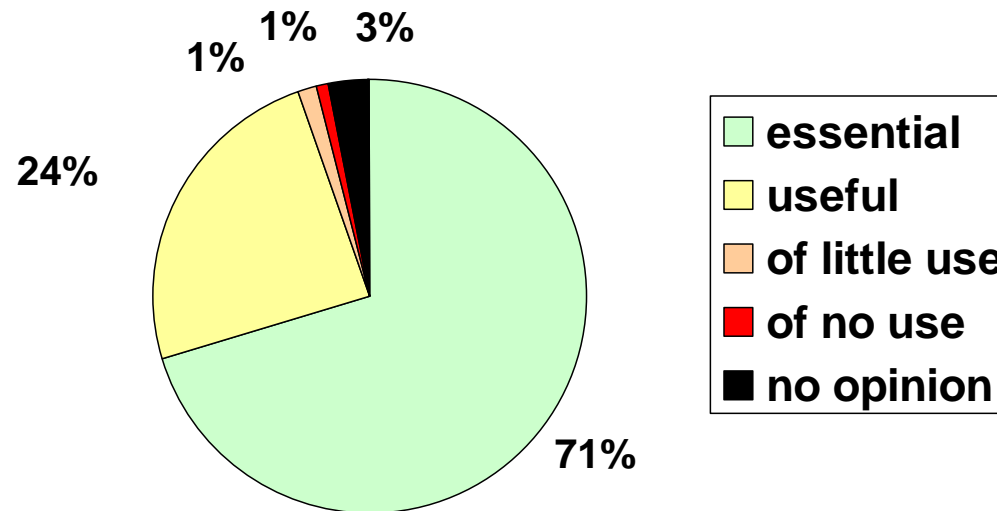
Diversity in medical needs of RD patients



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

Need for co-ordination

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

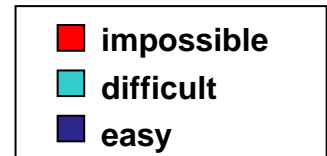
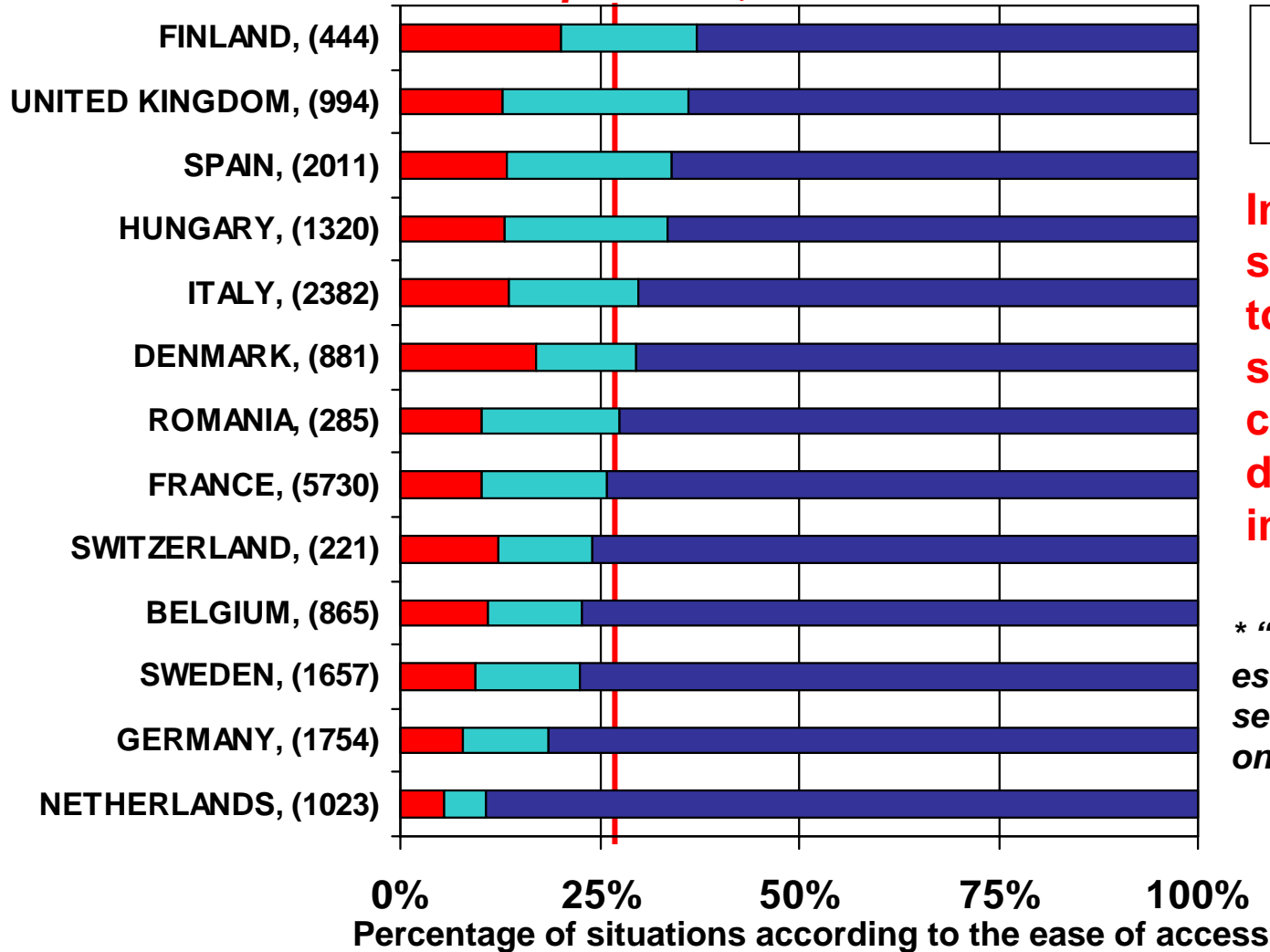


Third set of observations

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%

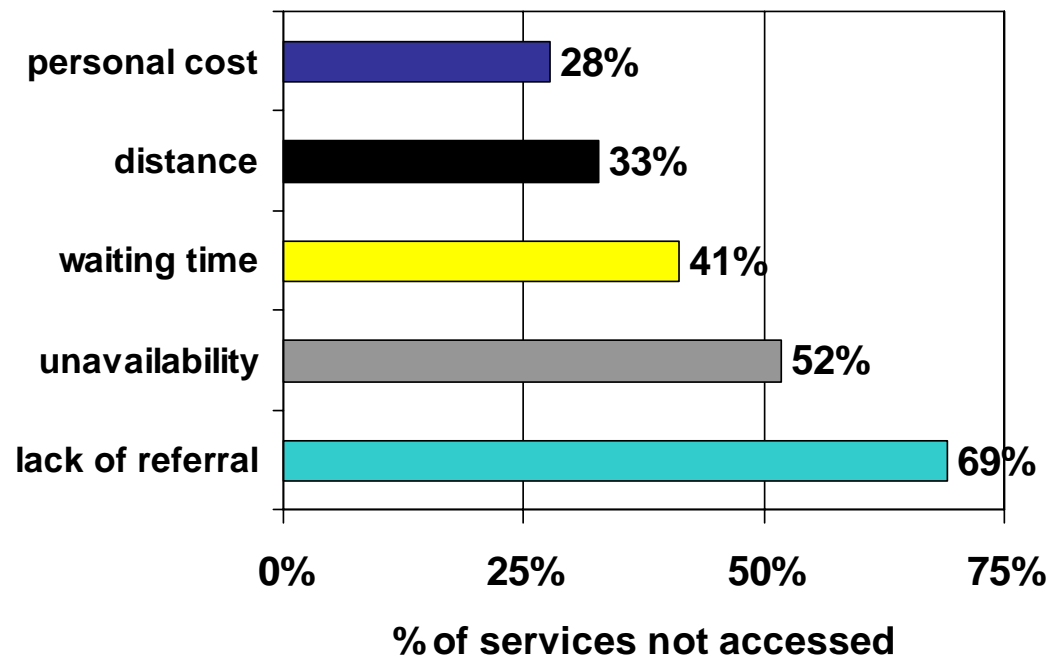
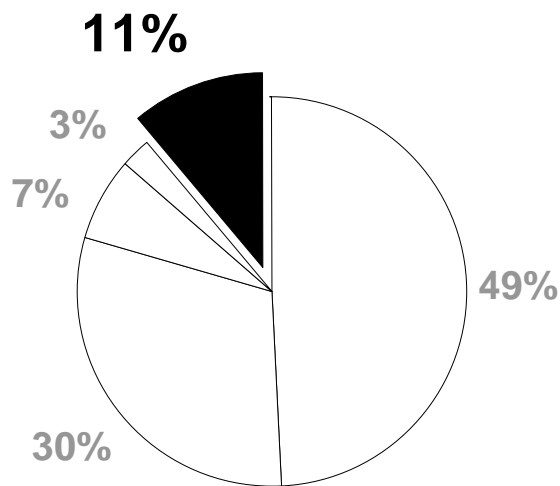


In more than ¼ of situations access to medical services was considered difficult or impossible

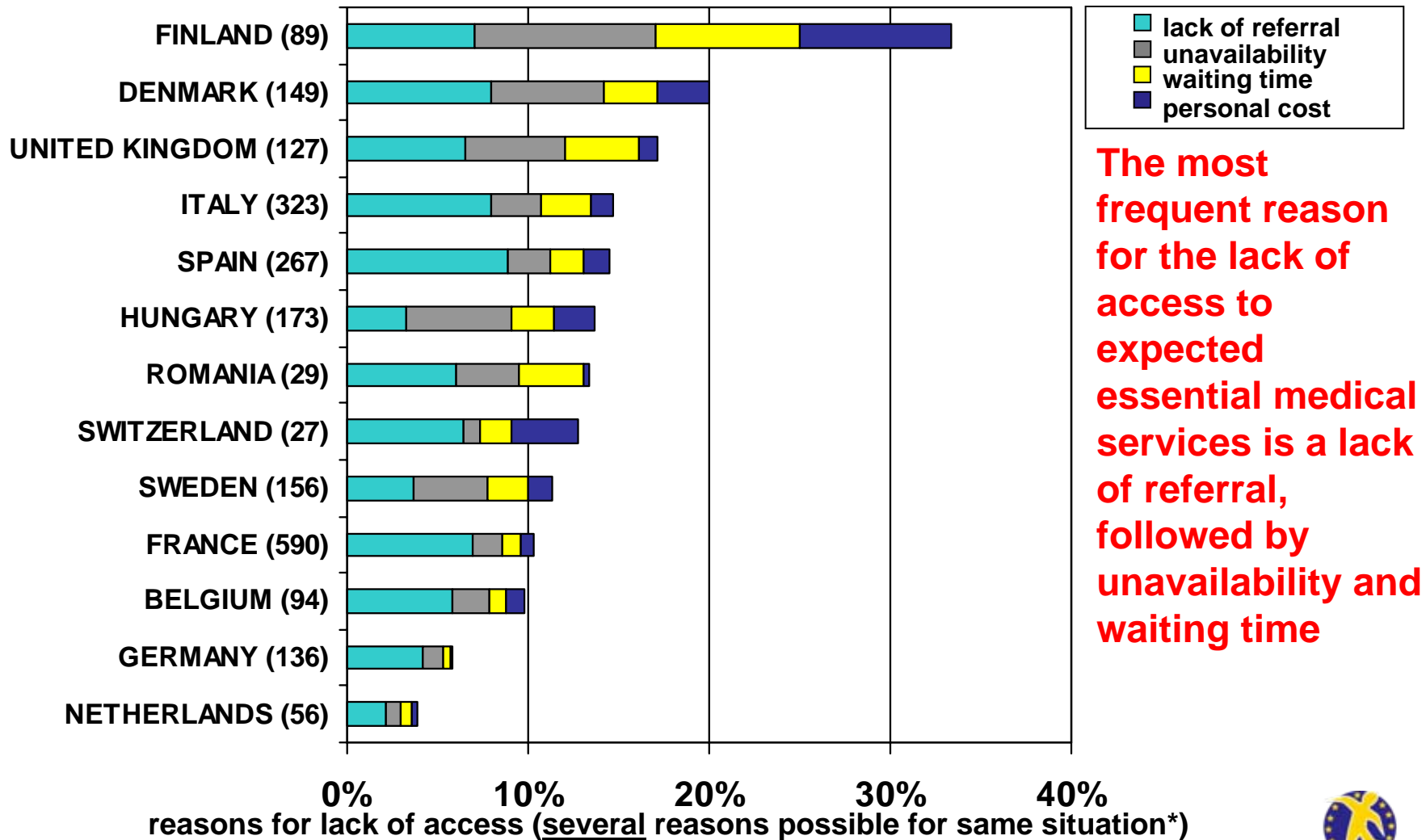
* *“situation”*: one essential medical service expected by one patient

Lack of access to essential medical services needed

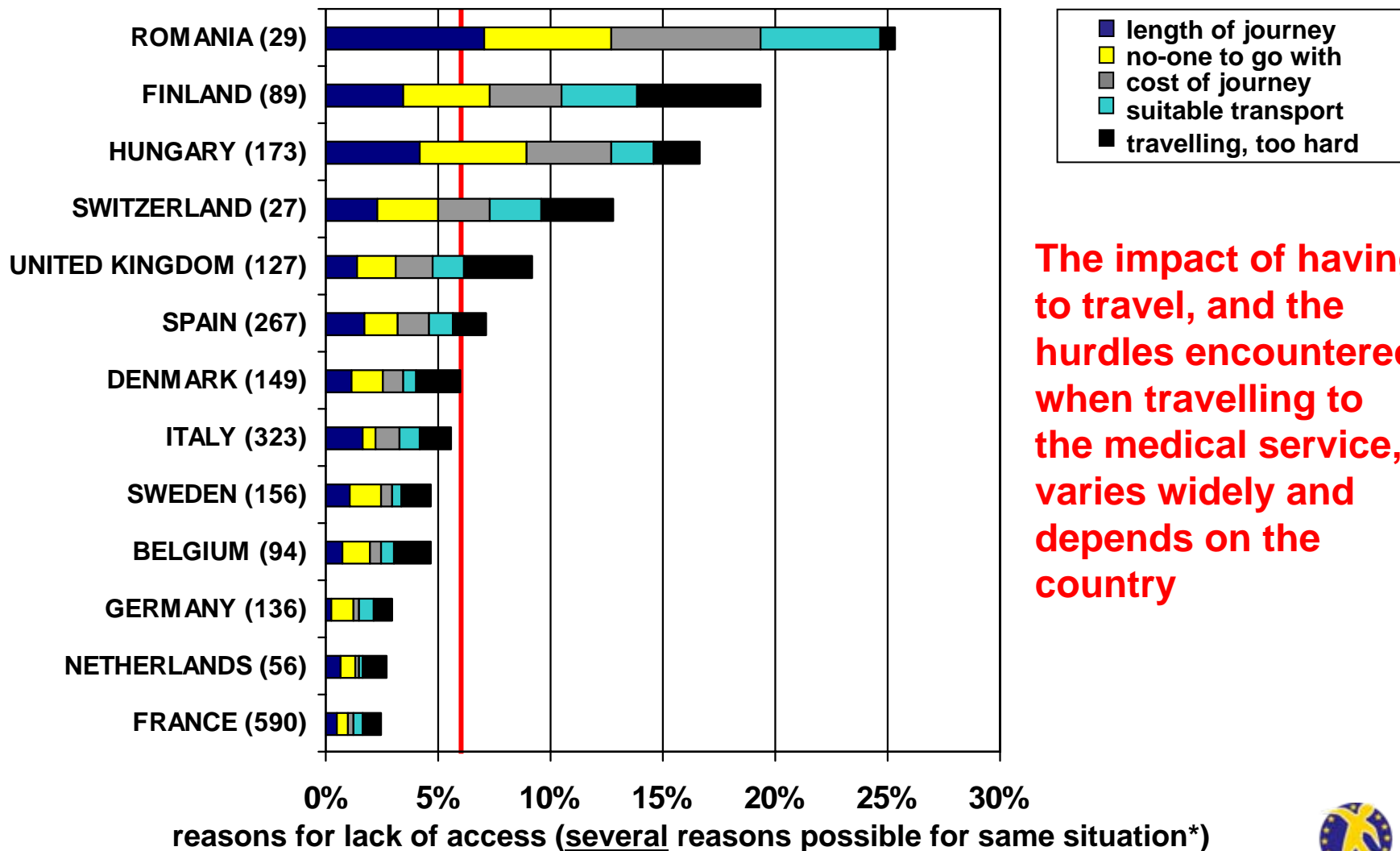
**Of the 11% with no access,
69% of these were due to lack of referral**



Reasons for lack of access to medical services, excluding travel



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 on referring**
- ➡ **Information tools, to guide and orientate (Orphanet, Helplines)**

Fourth set of observations

**Rare disease patients need an
integrated medical and social approach**

Social services: an essential issue to address

Rare disease patients need

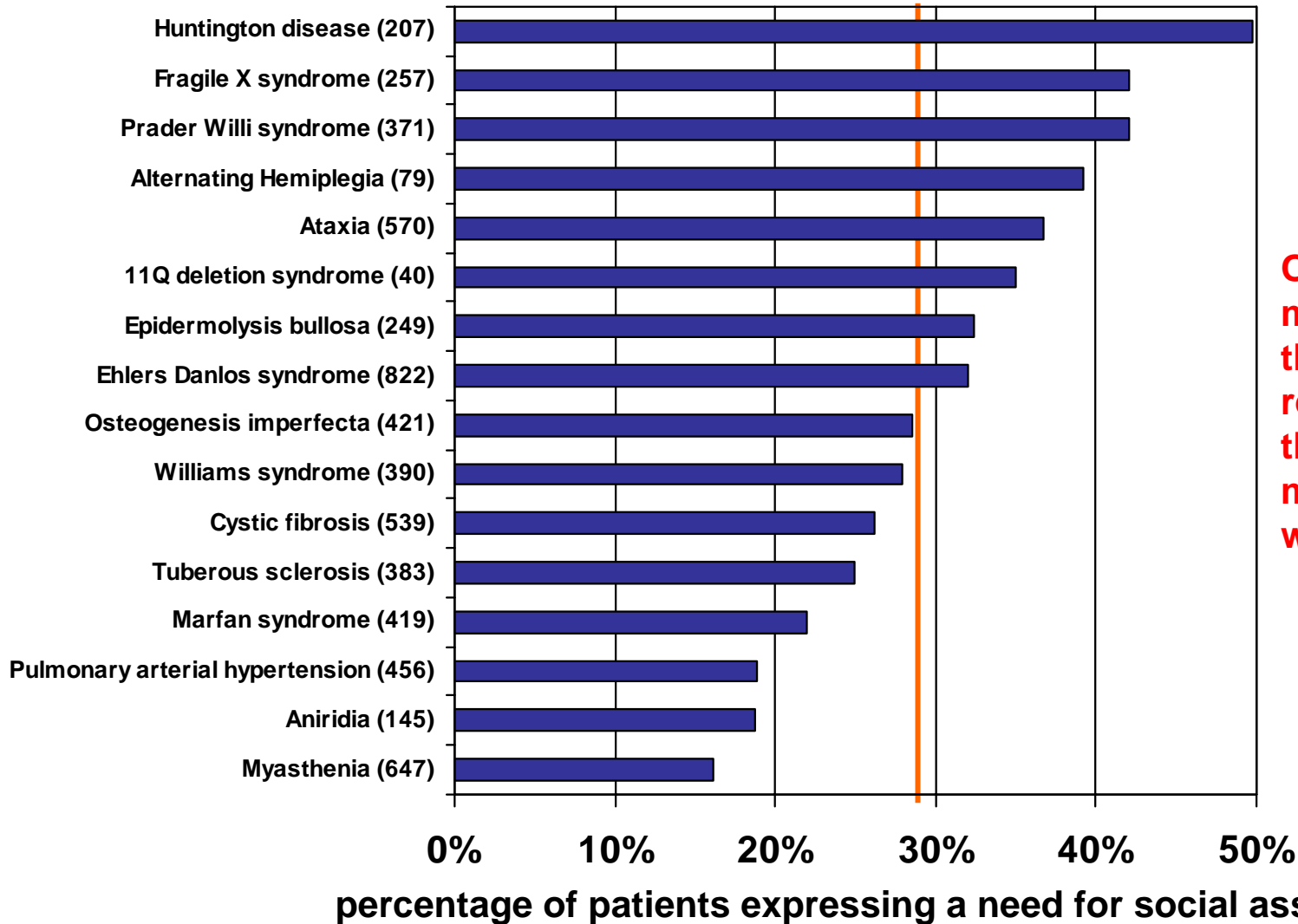
- **More and easier access**
- **Better quality of social services**

Key findings:

- **patient 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

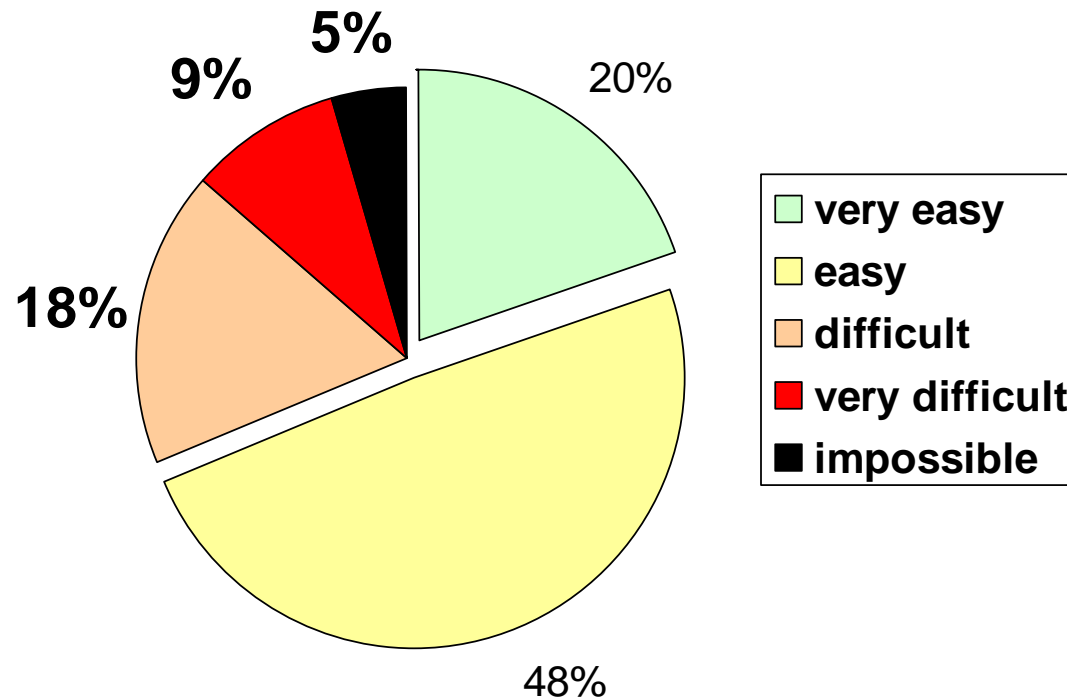
Overall: 29 %



Over the last 12 months, almost a third of patients responded that they needed to meet with a social worker

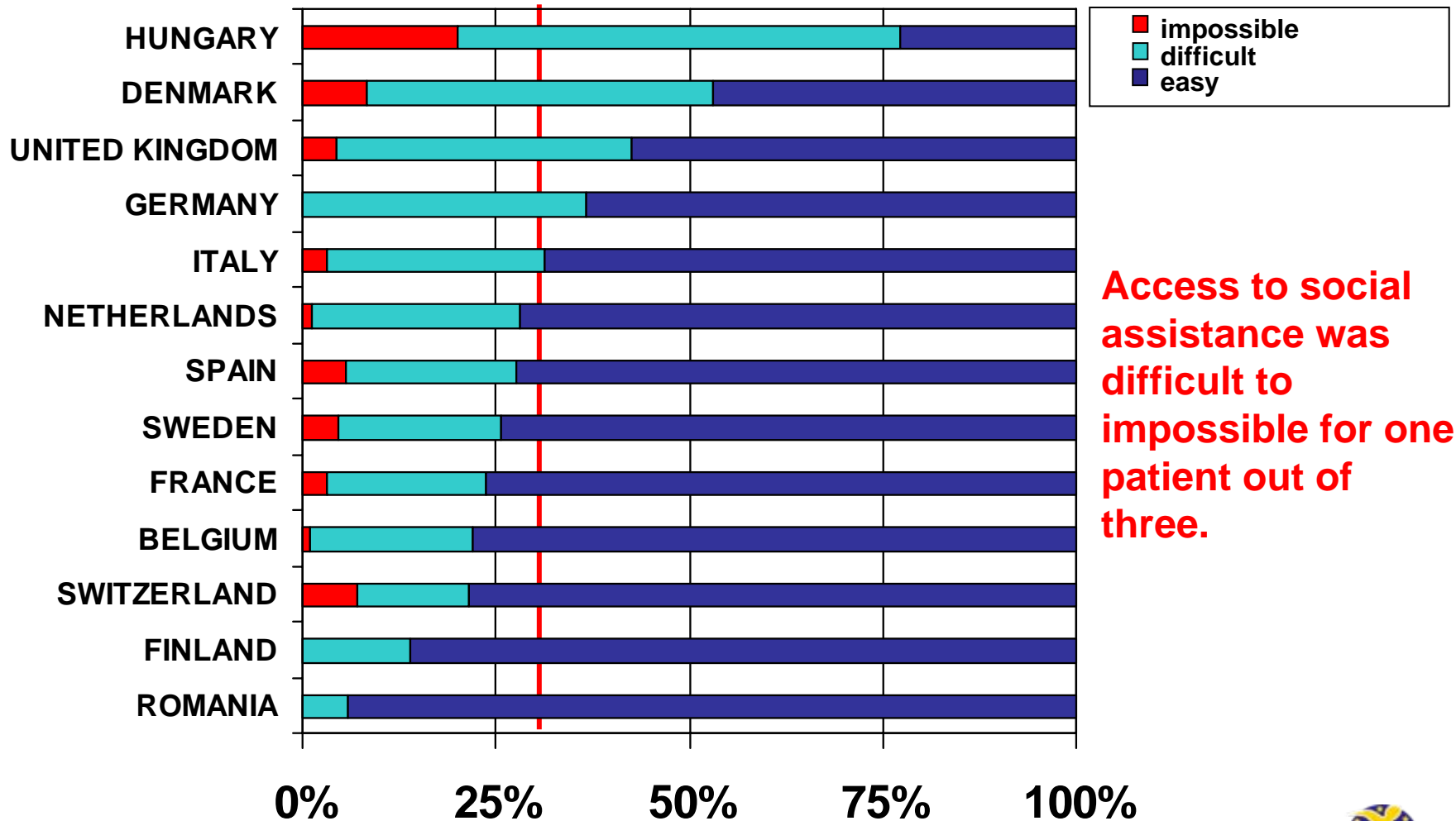
Access to Social Assistance

32% of patients said it was difficult or impossible to access social assistance



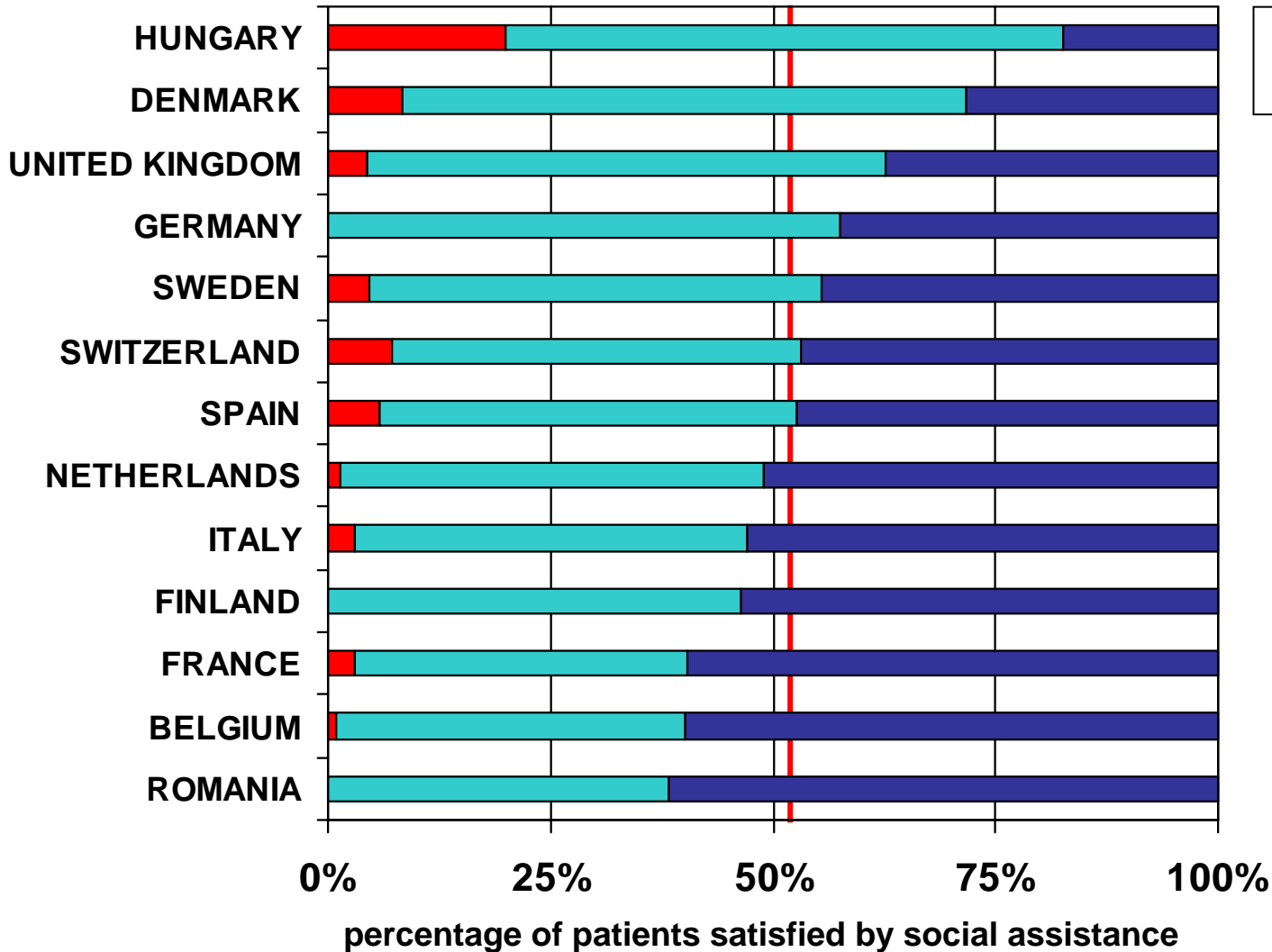
Access to social assistance

Difficult or Impossible, overall: 32%



Satisfaction with social assistance

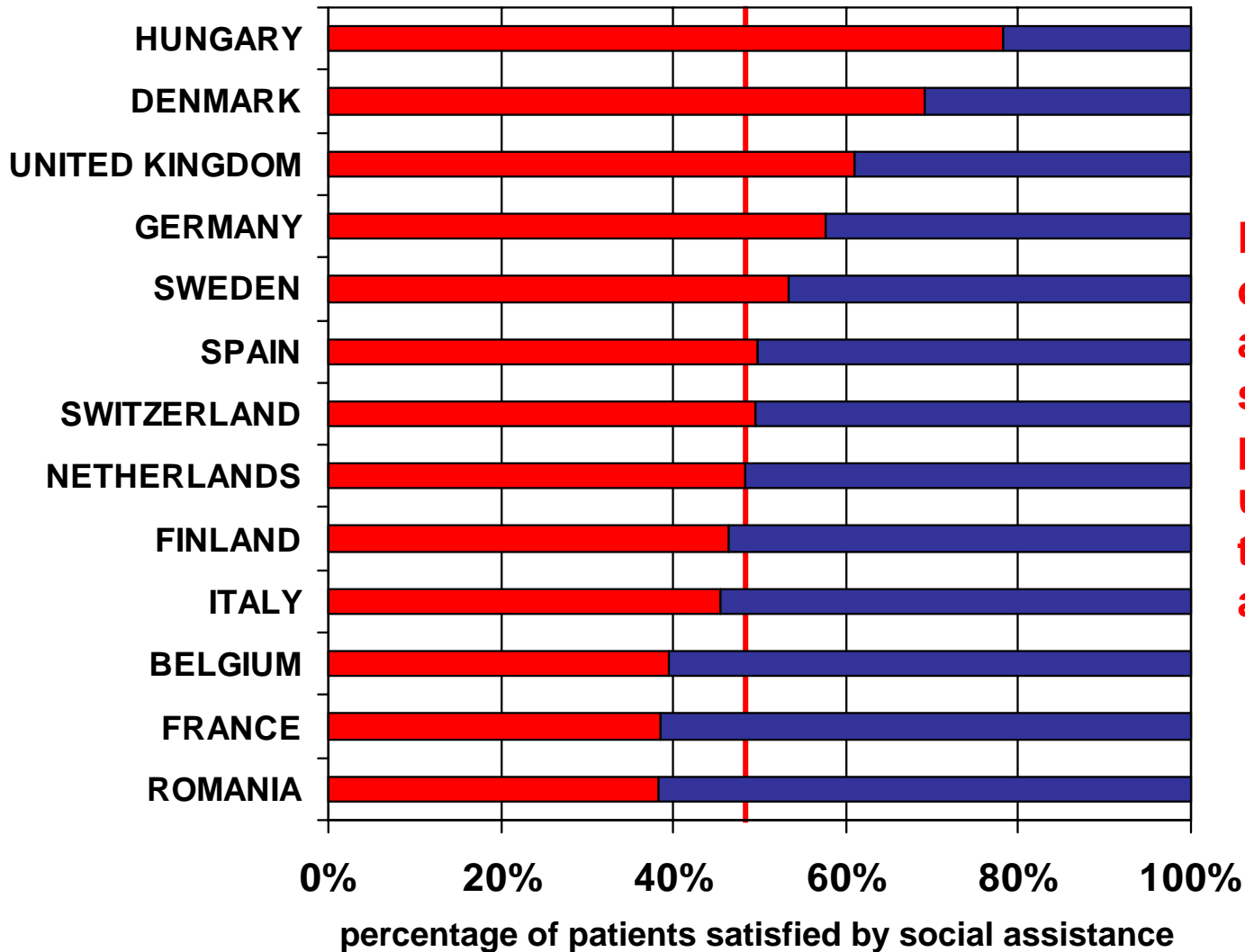
Lack of access or Unsatisfied, overall: 52%



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

Satisfaction with social assistance

Unsatisfied, overall: 48%



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 approach**
- **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 are 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