



**EURORDIS MEMBERSHIP MEETING DUBROVNIK**

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# **Progress report: the National plan in Croatia**

**Ingeborg Barisic**

**Children's Hospital Zagreb**

**Medical School University of Zagreb**

**[Ingeborg.barisic@kdb.hr](mailto:Ingeborg.barisic@kdb.hr)**

# Croatia – basic information



- ❖ **Area: 56,594 km<sup>2</sup>**
- ❖ **Population: 4.437.460**
- ❖ **Affected with rare diseases: 300,000**

# Croatia – basic information

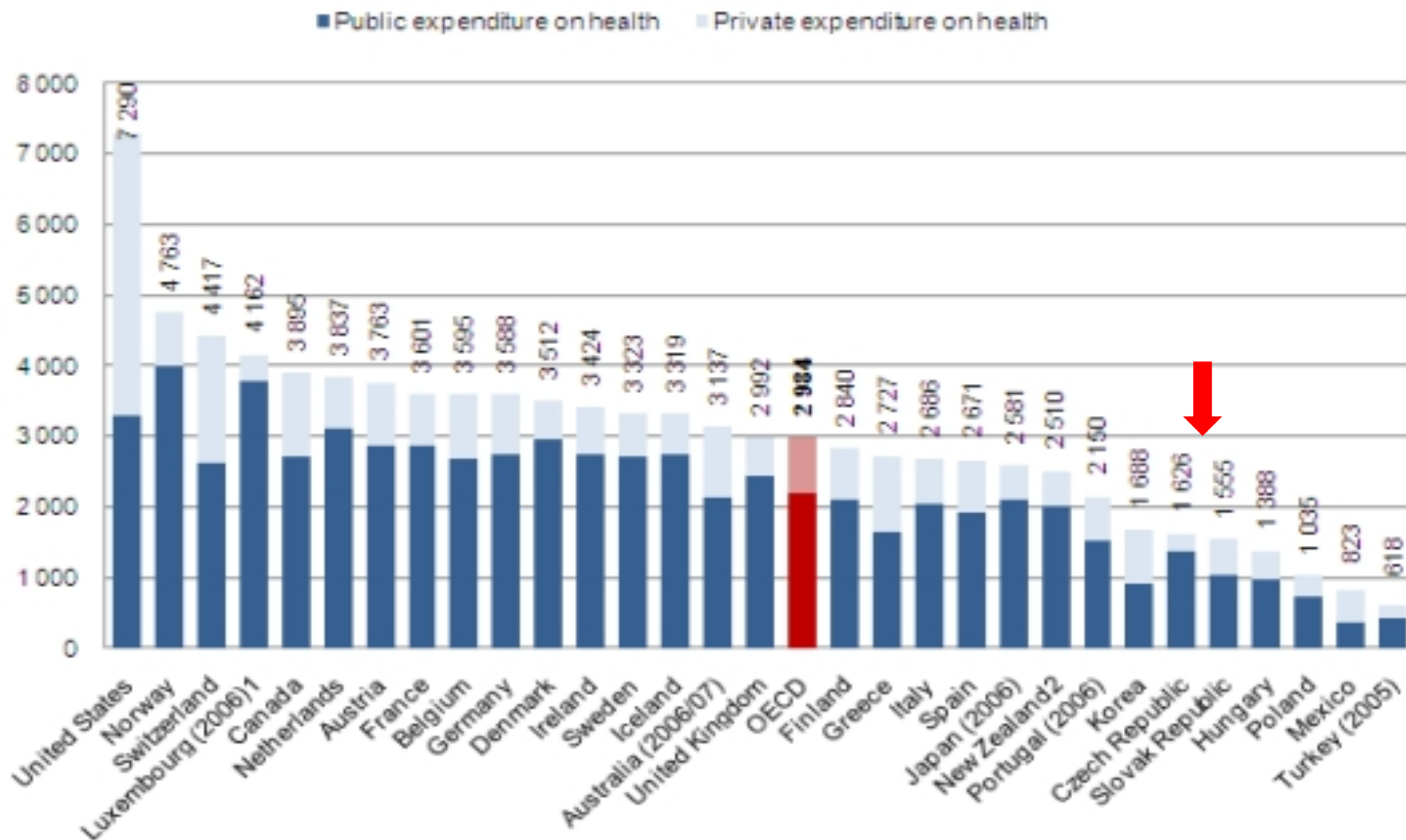
Total population	4.437.460
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Gross national income per capita (PPP international \$)	18,760
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Total expenditure on health per capita (Intl \$, 2011)	1,573
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Total expenditure on health as % of GDP (2011)	7.8
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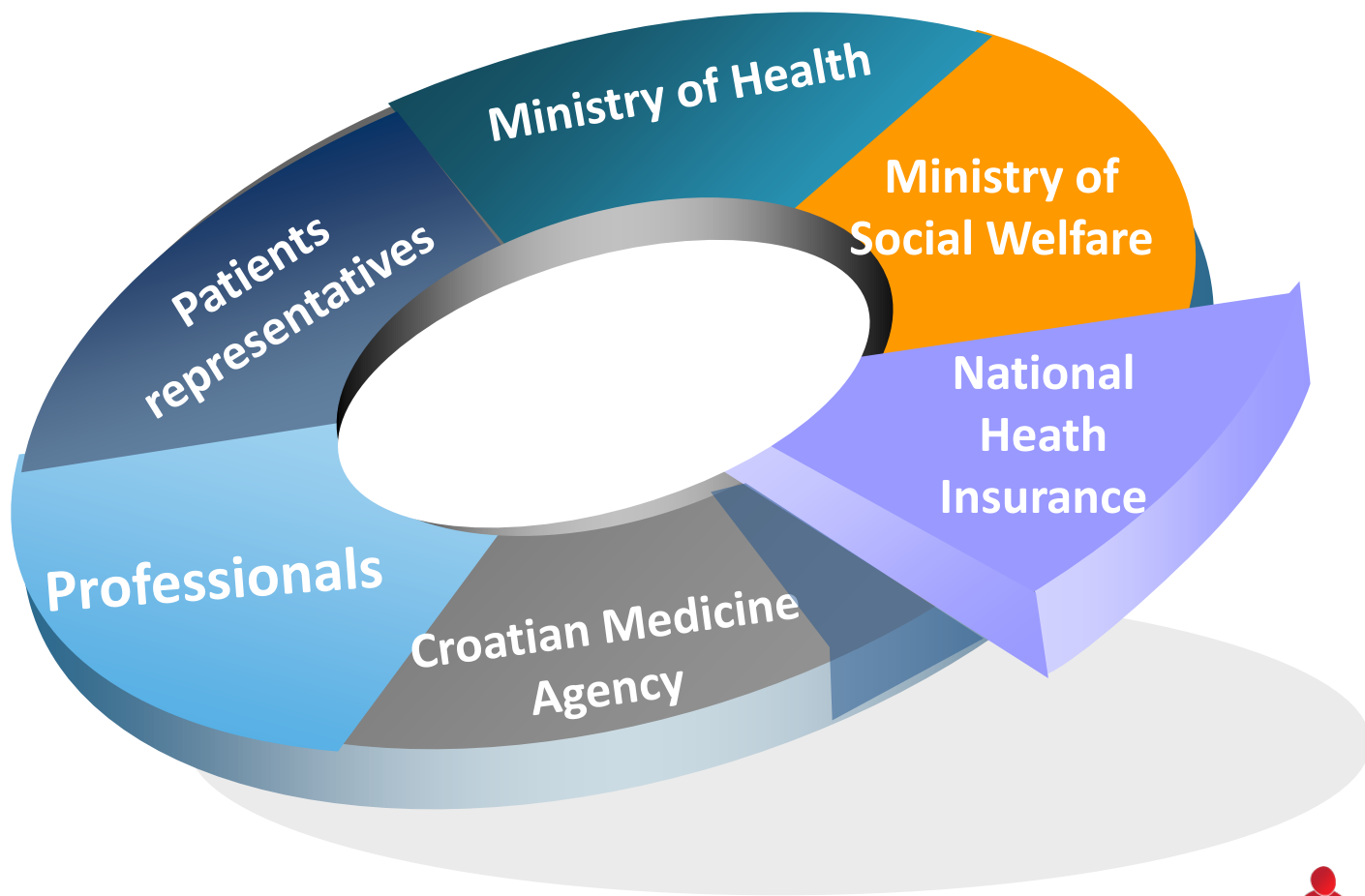
# Expenditure on health in EU and some Non-EU countries



# EURODISCARE 2 (2004) & 3(2007)

- ❖ 25% of patients had to wait for diagnosis between 5 and 30 years
- ❖ 40% at first received erroneous diagnosis
- ❖ To 30% the diagnosis was announced unsatisfactorily
- ❖ 12% of patients failed to access at least one of the 8 essential health services
- ❖ 70% of patients needed the services of a social worker, but in 30% of cases, the access to this service was difficult;
- ❖ In 60% of cases, at least 1 person in the household had to reduce his/her workload or stop working altogether
- ❖ 18% had to move house because of the disease
- ❖ 25% had to travel to different regions, 2% to a different country for diagnosis

# Committee for the drafting and development of the National plan for Rare Diseases



# First national EUROPLAN conference

**Dubrovnik, Croatia, Sept 17 to 19, 2010**

- ❖ In the framework of EUROPLAN, the first national conference on rare diseases took place in Dubrovnik, Croatia from Sept 17 to 19, 2010.







# Croatian National Plan for Rare Diseases Priority Areas

1. Promotion of the knowledge and information on RD

2. Support of rare disease registries

3. Facilitation of centres of expertise activities

4. Improvement of the health services for rare diseases

5. Improvement of access to treatment with OD

6. Securing the availability of special social services

7. Empowerment of patient's organisations

8. Encouraging research activities in the field of RD

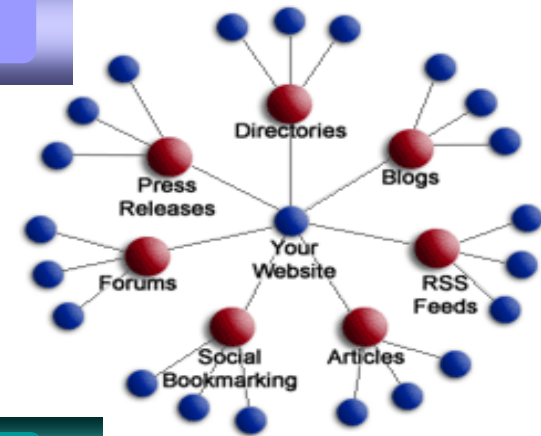
9. International networking in the field of rare diseases



# 1. Knowledge and information

## 1.1. Promote information

- general public
- patients and their families
- professionals



## 1.2. Improve education and training

- patients and their families
- professionals



# 2. Support of rare disease registries

1. Definition of EU accepted in 2009

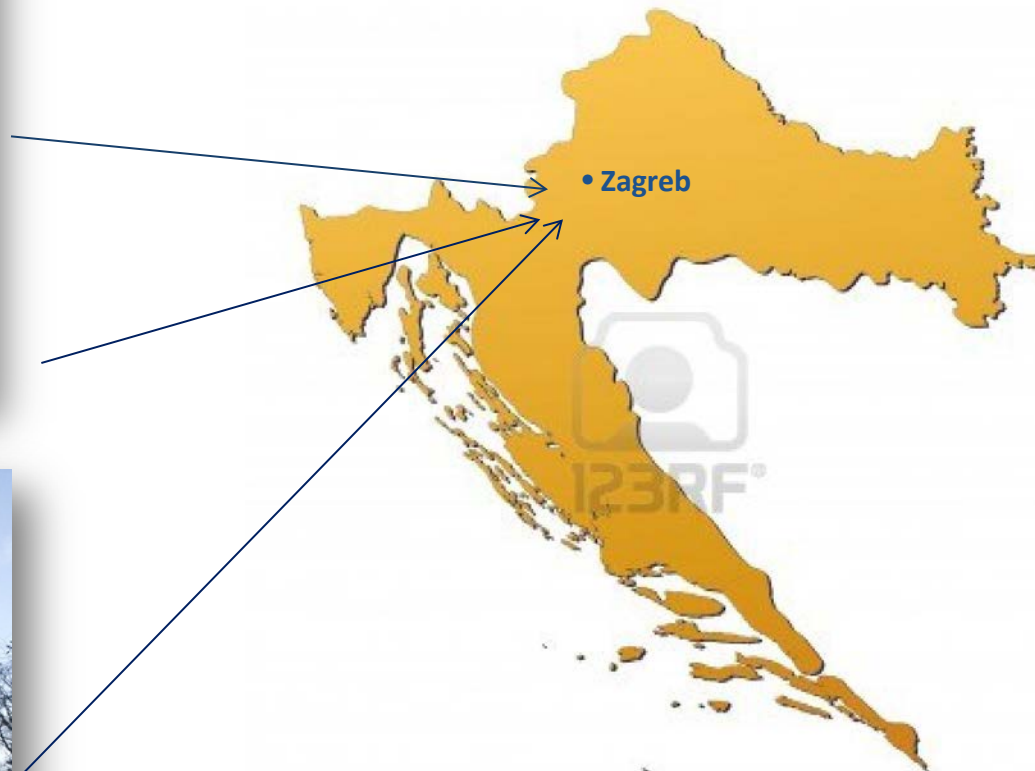
2. Adequate codification of RD

3. Inventoring of RD

4. Registries for RD



# 3. Centres of Excellence



# 4. Improvement of the health services



## 5. Orphan Drugs

- ❖ Croatian Institute for Health Insurance releases regular updates of the *List of Especially Expensive Drugs* which includes also expensive drugs for rare diseases
- ❖ Financed through the special fund, not from the hospital budget
- ❖ Orphan medicinal products approved for treatment of rare and severe diseases can be found on the web pages of the Croatian Agency for Drugs and Medicinal Products [www.halmed.hr](http://www.halmed.hr).
- ❖ Currently 32 products are on the list and as such reimbursed by the Croatian Institute for Health Insurance

## 6. Social services

- ❖ **Improve patients quality of life by supporting disability programmes and social services aimed at rare disease patients**
  - Education of social service professionals on RD
  - Development of the support services to families and carers at local level
  - Help lines
  - Respite care centres
  - Therapeutic recreational programmes
  - Involvement of patients organisations in development of programmes and regulations/legislation related to social care



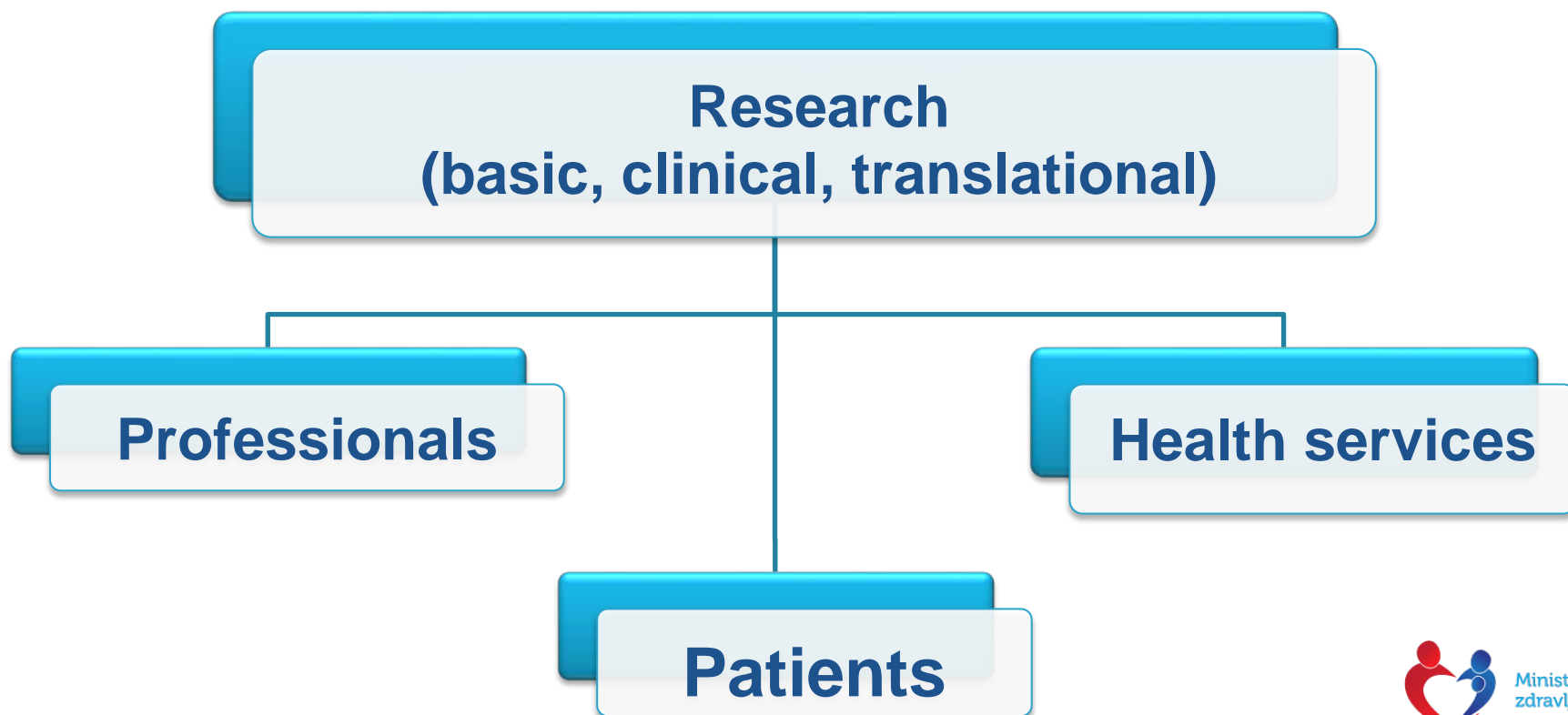
# 7. Empowerment of patients

- ❖ **Establish a mechanism that ensures that patients are empowered to directly contribute to shaping healthcare policies that affect their lives**
  - Involvement in drafting and follow up of the National plan
  - Partnership with Centres of Excellence
  - Involvement in all decision-making processes
  - Funding



# 8. Research

- ❖ Support research programmes for RD
- ❖ Recruitment of young scientists
- ❖ Ensure funds for the research programme



# 9. Networking

## 1. Patients



Hrvatski savez  
za rijetke bolesti

## 2. Professionals

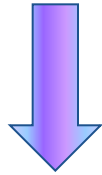


## 3. Research



# Progress of the National Plan

May 2010 – Dec 2012



Phase 1

Phase 2

Phase 3

Phase 4

Drafting of  
the National  
Plan

Approval of  
the  
Ministry of  
Health

Public  
Conslutation

Approval  
of the  
Parliament



# Thank You !

[ingeborg.barisic@kdb.hr](mailto:ingeborg.barisic@kdb.hr)

Committee for the Croatian National Plan for RD  
Ministry of Health of the Republic of Croatia