EUROPLAN
European Project for Rare Diseases National Plans Development
Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health
2012-2015

EUCERD
Joint Action

Co-funded by the European Commission

Executive Agency for Health and Consumers

EURORDIS Membership Meeting 2013 - Workshop 2: Funding for National Plans

SQUARING THE CIRCLE

how EU Member States fund National Plans

Domenica Taruscio

EUROPLAN Leader

Italian National Centre for Rare Diseases
Italian Institute of Health
Rome, Italy

A National plan for rare diseases

an official strategic public health document,
accepted by the government,
containing specific priorities, actions, timetable
for implementation and a dedicated budget
(EUROPLAN definition)

not only for the RD stakeholders,
but for the whole society.

National Plan

a strategic activity,
which aims optimization and integrity of limited resources
(both human, financial and material).

A KEY FACTOR

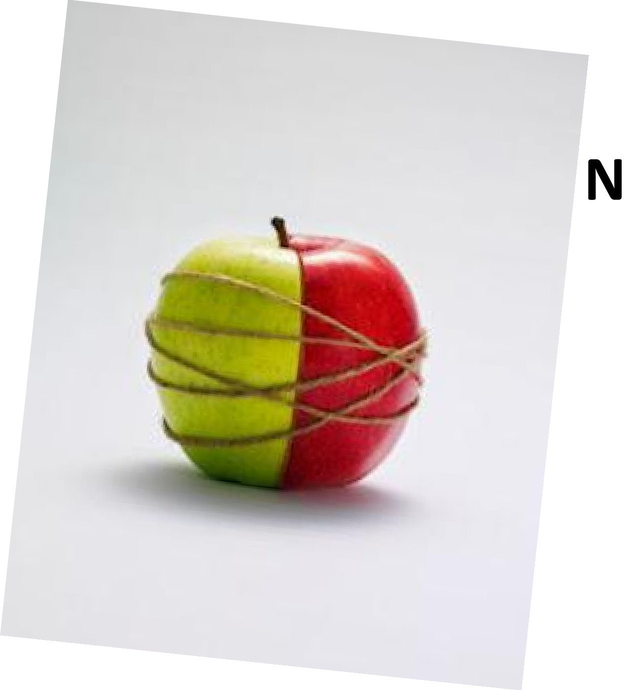
for nowadays national health systems,
which often struggle to meet the criteria of efficiency and cost-effectiveness of public funds utilization.

Rare Diseases National Plans

the common denominator of modern day RD public health policy

EUROPEAN
COMMON OBJECTIVE

to ensure equal access and availability of prevention, diagnosis, treatment and rehabilitation for people with RD



NATIONAL AUTHORITIES
RIGHT

to choose which specific measures to approve and implement

EU Council Recommendation and EUROPLAN Recommendation

AREA 1. plans and strategies in the field of rare diseases

AREA 2. adequate definition, codification and inventorying

AREA 3. research on rare diseases

AREA 4. centres of expertise and european reference networks for rare diseases

AREA 5. gathering the expertise on rare diseases at european level

AREA 6. empowerment of patient organizations

AREA 7. sustainability

Budget for National Plans / Strategies (1)

COUNTRY	ALLOCATED FUNDING
BELGIUM	+
BULGARIA	+
CZECH REPUBLIC	
FRANCE	+
GERMANY	-
GREECE	-
ITALY	-
NETHERLANDS	+
PORTUGAL	- (Directorate General of Health and Office of the High Commissioner for Health have co-funded a few projects RD)
ROMANIA	-
SLOVAK REPUBLIC	-
SLOVENIA	-
SPAIN	-|

Budget for National Plans / Strategies (2)

COUNTRY	ALLOCATED FUNDING
DENMARK	-
IRELAND	-
LUXEMBOURG	-
UNITED KINGDOM	-

EU COUNTRY	IRDiC	E-RARE
AUSTRIA		√
BELGIUM		√
FRANCE	√	√
GERMANY	√	√
GREECE		√
HUNGARY		√
ITALY	√	√
NETHERLAND	√	√
IRELAND	√	
POLAND		√
PORTUGAL		√
ROMANIA		√
SPAIN	√	√
UNITED KINGDOM	√	

Public Health

EUROPLAN

EUROPLAN

European Project for Rare Diseases National Plans Development

Funded: European Commission Public Health Program 2003-08

Priority area: 1. Health Information (HI 2007).

Action: 1.4 Developing strategies for information exchange and responding to non-communicable health threats

Contract Number: 101120 - 2007119

Project Coordinator: Domenica Taruscio (ISS)

Main Partner: Istituto Superiore di Sanità (Italy)

Associated partners: 10

Project Period: 1 April 2008 – 31 March 2011

Referring Period: 1 June 2010 – 31 December 2010

RECOMMENDATIONS

FOR THE DEVELOPMENT OF NATIONAL PLANS FOR RARE DISEASES

GUIDANCE DOCUMENT

Guidance Doc EUROPLAN 20100601

Document Authors: All EUROPLAN partners

Revision Date: 8 July 2010

Diffusion Level: Public Document

Intended Target: Participants of the 16 National Conferences

Key words: Recommendations, National Plans, Rare Diseases

EUROPLAN Draft version. Selecting indicators to evaluate the achievements of RD initiatives

1

EUROPLAN

European Project for Rare Diseases National Plans Development

European Project for Rare Diseases National Plans Development (EUROPLAN)

Selecting indicators to evaluate the achievements of RD initiatives

By WP5: Manuel Posada, Manuel Hens, Maria José Carroquino and EUROPLAN Working Group on Indicators

Rare Diseases Research Institute
Instituto de Salud Carlos III

Madrid March, 29th, 2010

Advanced Draft EUCERD Recommendations on Core Indicators for Rare Disease National Plans

EUCERD
European Union Committee of Experts on Rare Diseases

EUCERD RECOMMENDATIONS
ON CORE INDICATORS
FOR
RARE DISEASE NATIONAL
PLANS/STRATEGIES

FOR ADOPTION
8th EUCERD Meeting 5-6 June 2013

1

EUROPLAN RECOMMENDATIONS

EUROPLAN INDICATORS

EUCERD RECOMMENDATIONS on CORE INDICATORS

FINANCIAL ASPECTS
In EUROPLAN Recommendations

Area	Recommendations
1. Plans and strategies in the field of Rare Diseases	**R 1.9** **Appropriate resources** are allocated to ensure the feasibility of the actions in the planned time. **R 1.11** Measures are taken to ensure the **sustainability**, transfer and integration of the actions foreseen by the national plan or strategy into the general health system of the country.
3. Research on Rare Diseases	**R 3.1** Dedicated national research programs for rare diseases (basic, translational, clinical, public health and social research) are established and supported with **dedicated funds, preferably for a long period**. Research projects on rare diseases should be made identifiable and traceable within broader national research programs. **R 3.4** Proper initiatives are developed to foster participation in cooperative international research initiatives on rare diseases, including the EU framework program and E-RARE. The **national funding of these initiatives should be increased considerably**. **R 3.7** Specific programs are launched for **funding** and/or recruitment of young scientists on rare diseases research projects.
5. Gathering the expertise on Rare Diseases at European level	**R 5.12** An inventory of orphan drugs accessible at national level, including **reimbursement** status, is compiled and made publicly available. **R 5.13** Patients' access to authorised treatment for rare disease including **reimbursement** status, is recorded at national and/or EU level.
6. Empowerment of patient organisations	**R 6.5** Specialised social services are **supported** for people living with a chronically debilitating rare disease and their family carers. **R 6.8** Interactive information and support services for patients are promoted (such as help lines, e-tools etc).

FINANCIAL ASPECTS
in the EUROPLAN Recommendations

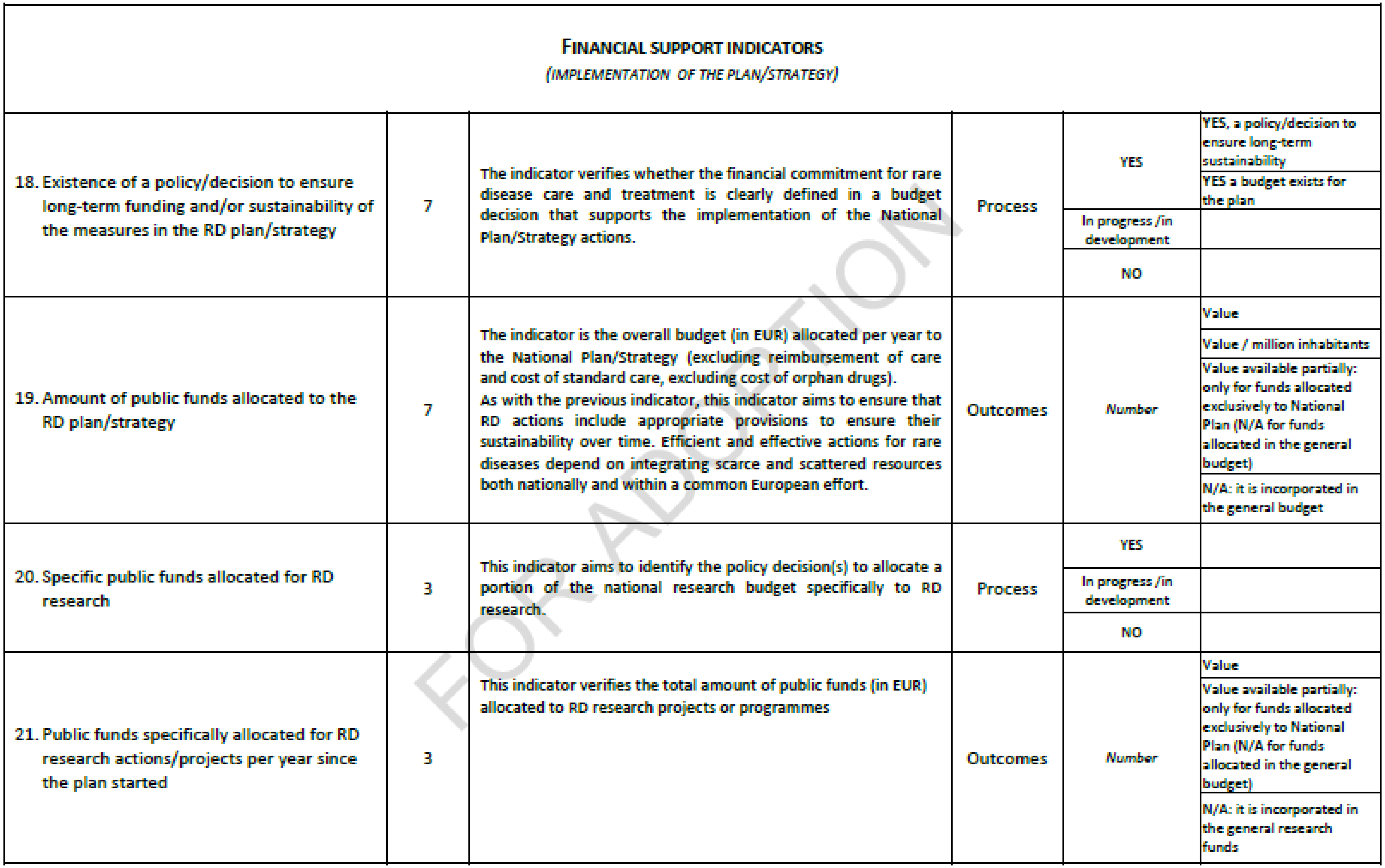
Area	Recommendations
7. Sustainability	R 7.1 The National Plan or Strategy on rare diseases is supported **combining national (regular and ad hoc) and European funds**, according to the country health system and decision-making processes. R 7.2 Possibilities for European **funding** are exploited for those parts of National Plans or Strategies which are in the scope of the European Social Fund and European Regional Development Fund. R 7.3 The cooperation with other member states is envisaged when cross-border health care is needed, in order to address the need for sustainability of common European infrastructures, **share costs** and maximise the efficacy of initiatives. R 7.5 Agreements for coordinated projects, including **long-term sustainability** of common infrastructures, are pursued.

FINANCIAL ASPECTS
in the EUROPLAN Indicators

Area	Action	Indicator
1. Plans and strategies in the field of Rare Diseases	Establishing of a budget for developing the plan/strategy	1.7 - Budget of plan/strategy
3. Research on Rare Diseases	Allocate funds for the RD research programme	3.9 - There are specific public funds allocated for RD research 3.10 - Funds specifically allocated for RD research actions/projects per year since then plan started
5. Gathering the expertise on Rare Diseases at European level	Gathering the expertise on Rare Diseases at European level	5.12 - Number of ODD reimbursed 100%
6. Empowerment of patient organisations	Support the activities performed by including patient organizations, such as awareness raising, capacity-building and training, exchange of information and best practices, networking, outreach to very isolated patients	6.8 - Resource (funding) provided for supporting the activities performed by patient organizations
7. Sustainability	Ensure through appropriate funding mechanisms the long-term sustainability of infrastructures developed in the field of information, research and healthcare for rare diseases	7.2 - Amount of funds allocated for ensuring RD plan /strategy sustainability

FINANCIAL ASPECTS

in EUCERD RECOMMENDATIONS ON CORE INDICATORS FOR RD NP/NS (draft for adoption)



FINANCIAL SUPPORT INDICATORS

(IMPLEMENTATION OF THE PLAN/STRATEGY)

18. Existence of a policy/decision to ensure long-term funding and/or sustainability of the measures in the RD plan/strategy	7	The indicator verifies whether the financial commitment for rare disease care and treatment is clearly defined in a budget decision that supports the implementation of the National Plan/Strategy actions.	Process	YES	YES, a policy/decision to ensure long-term sustainability YES a budget exists for the plan
				In progress /in development	
				NO	
19. Amount of public funds allocated to the RD plan/strategy	7	The indicator is the overall budget (in EUR) allocated per year to the National Plan/Strategy (excluding reimbursement of care and cost of standard care, excluding cost of orphan drugs). As with the previous indicator, this indicator aims to ensure that RD actions include appropriate provisions to ensure their sustainability over time. Efficient and effective actions for rare diseases depend on integrating scarce and scattered resources both nationally and within a common European effort.	Outcomes	*Number*	Value
					Value / million inhabitants
					Value available partially: only for funds allocated exclusively to National Plan (N/A for funds allocated in the general budget)
					N/A: it is incorporated in the general budget
20. Specific public funds allocated for RD research	3	This indicator aims to identify the policy decision(s) to allocate a portion of the national research budget specifically to RD research.	Process	YES	
				In progress /in development	
				NO	
21. Public funds specifically allocated for RD research actions/projects per year since the plan started	3	This indicator verifies the total amount of public funds (in EUR) allocated to RD research projects or programmes	Outcomes	*Number*	Value
					Value available partially: only for funds allocated exclusively to National Plan (N/A for funds allocated in the general budget)
					N/A: it is incorporated in the general research funds

RD National Plans/Strategies
AT A GLANCE

All EU Member States are currently preparing their plans or strategies.

All documents
(in original languages and, if existing, in english)
are available at
www.europlanproject.eu

BELGIUM

Recommendations and proposals for the Belgian National Plan for Rare Diseases (2010)

- The Belgian Plan **has well specified objectives and actions to be supported by a budget**, implemented within a time frame, and evaluated with specific indicators.

- If the proposed measures are successfully implemented, this will – in addition to various savings – generate **an extra health insurance cost estimated at between € 9 million (during the first year) to € 30 million per year (after 5 years, most successfully scenario)**. Such expenditure will be linked mainly to the Centres of Expertise.

- The **implementation of the Belgian Rare Diseases Plan also implies a budget of around €1 million** for the costs of running it, setting up international networks, communication and evaluation.

BELGIUM

Recommendations and proposals for the Belgian National Plan for Rare Diseases (2010)

A specific budget impact analysis

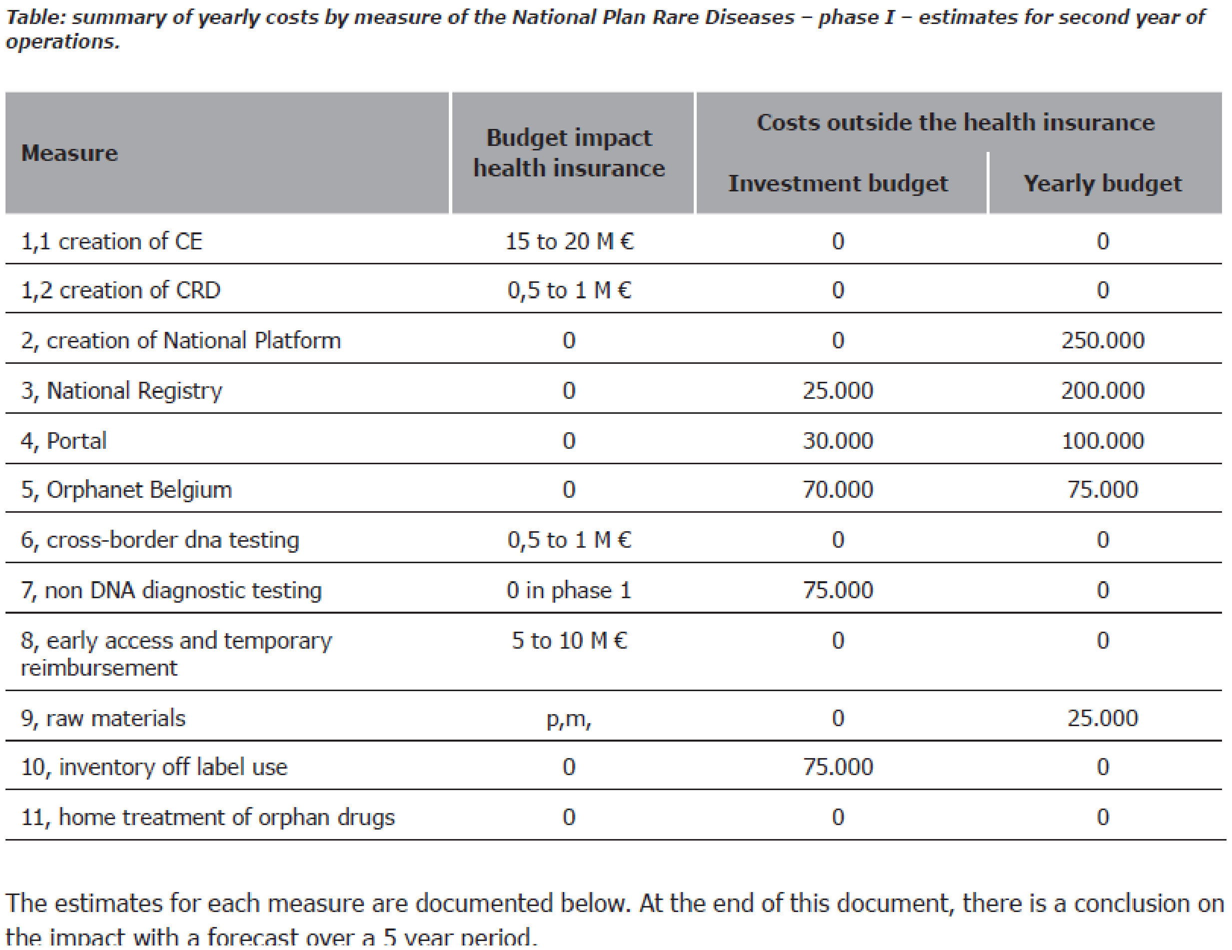


Table: summary of yearly costs by measure of the National Plan Rare Diseases – phase I – estimates for second year of operations.

Measure	Budget impact health insurance	Costs outside the health insurance	
		Investment budget	Yearly budget
1,1 creation of CE	15 to 20 M €	0	0
1,2 creation of CRD	0,5 to 1 M €	0	0
2, creation of National Platform	0	0	250.000
3, National Registry	0	25.000	200.000
4, Portal	0	30.000	100.000
5, Orphanet Belgium	0	70.000	75.000
6, cross-border dna testing	0,5 to 1 M €	0	0
7, non DNA diagnostic testing	0 in phase 1	75.000	0
8, early access and temporary reimbursement	5 to 10 M €	0	0
9, raw materials	p,m,	0	25.000
10, inventory off label use	0	75.000	0
11, home treatment of orphan drugs	0	0	0

The estimates for each measure are documented below. At the end of this document, there is a conclusion on the impact with a forecast over a 5 year period.

BULGARIA

National Plan on Rare Diseases 2009-2013 (2010)

- A National Consulting Council on Rare Diseases has been established by the Ministry of Health, and meets once a month to supervise the progress and implementation of the plan: the Council includes medical professionals, Ministry representatives and a representative of the National Alliance of People with Rare Diseases.

- Although the **estimated budget of the Plan is € 11.3 million,** **the assigned funds are much less and are disproportionally distributed** (i.e. directed towards genetic testing activities).

  The estimated budget **does not take into account the costs for the provision of clinical services** for rare disease patients.

CZECH REPUBLIC

- *Czech National Strategy for Rare Diseases 2011-2013*
- *Czech National Plan for Rare Diseases 2012-2014*

Czech National Strategy for Rare Diseases 2011-2013

- **A budget has not yet been announced and is in the process of substantiation** by the Taskforce.

- **The Ministry of Health has been trying to assure funding within the frame of the EEA Norway Grants scheme** (2008-2014) for the National Coordination Centre at University Hospital Motol and via annual Ministry of Health targeted appropriation schemes, both which have deadlines in June 2012.

Czech National Action Plan for Rare Diseases 2012-2014

- identifies priority tasks and activities that will be implemented in the years 2012 to 2014

- ..tasks, tools, responsibilities, deadlines, **financial resources** and indicators **have been set so that they are feasible and have a minimum financial impact on the central government budget and public health insurance funding**.

FRANCE

- ***French National Plan on Rare Diseases (2005-2008)***
- ***Plan National des Maladies Rares (2010-2014)***

- The **first EU country to adopt**, at the end of 2004, **a comprehensive rare disease plan with allocated funding**.
- The **second plan** was launched on 28 February 2011 on the occasion of Rare Disease Day, **with a budget of € 180 million**.
- The second French National Plan for Rare Diseases was elaborated by the Ministry of Health during 2009-2010 from the results of the evaluation of the first plan and from the conclusions of seven working groups, which had gathered during 34 meetings 184 representatives of health professionals, rare disease experts, researchers, patient organisations and administration.

GERMANY

Measures to improve the health situation of persons with rare diseases in Germany (2009)

- There is no national plan for rare diseases in Germany at the moment, and there are **no specific funds allocated to rare diseases in the health care system, but a specific funding exists for research projects.**

- The German Federal Ministry for Education and Research (BMBF) funds **programmes on rare diseases research (starting in 2012 with more than € 21 million for three years)** and meeting of the networks for rare diseases.

- A **National RD Strategy should be ready in June 2013** and then presented to the Minister of Health.

GREECE

Greek National Plan on Rare Diseases 2008-2012

- **Although an initial estimate for the budget required** was made,
  no National funding has been officially allocated to the National Plan of Action for Rare Diseases
  EU infrastructural funds

- Most of the objectives of the proposed national plan are or could be incorporated in the existing structure and function of Greek National Health System (GNHS).

  Implementation of strategic priorities for RD is coordinated by the Ministry of Health and mainly by the Hellenic Centre of Disease Control and Prevention (KEELPNO) jointly to those of common diseases.

- **Some Patients associations are amongst the organisations which provide funding for the organisation and functioning of centres of expertise and expert units**.

- The **General Secretariat for Research and Technology** (Ministry of Education, Life Long Learning and Religious Affairs) **has been funding research projects coping with all aspects of rare diseases** (rare cancers included) **in the framework of "biomedical research"**.

ITALY

Italian National Plan for Rare Diseases 2013-2016 (draft)

- A National Plan for RD is currently under development.
- Actions in favour of patients with rare diseases since 2001 (D.M. 279/2001).
- **Care of patients with rare diseases is funded through the resources normally allocated to the National Health Service and allocated annually among the Regions**, with a level of expenditure is difficult to define but certainly varies between the regions.
- National and regional Registries of rare diseases
- National / Regional Networks of Centres for diagnosis and care
- Orphan drugs: 2011 costs for OD i 950.000 euro (AIFA)
- E-RARE
- IRDIRC

NETHERLANDS

Strategy of The Netherlands in the field of Rare Diseases (draft - 2012)

- In 1998 the **Ministry** initiated a national strategy with regard to rare diseases and orphan drugs and **provided funding to implement this strategy.**
- Most tasks are within the remit and expertise of (The Netherlands Organisation for Health Research and Development (ZonMw)
- **Extra funding for the stakeholders is not foreseen in the new strategy, with the exception of the funding of some projects by patient organisations**. The **Ministry** has however, with the remaining tasks in mind, **allocated specific funding to ZonMw, (€ 4 x € 100,000 supplemented with € 480,000 for the years 2012-2015).**
- Ministry indicated that the university medical centres should develop **referral centres** for patients with rare diseases. The **financial resources that the Ministry allocates to these medical centres via the Academic Component would then primarily be intended for the funding of care for patients with a rare disease** (or to care for patients that would need specialized non-standardized care) **and to the funding of research** in these fields. It is clear that diagnosis, treatment and research in the area of rare diseases are often not reimbursed via the usual procedures.
- The Academic Component can therefore, provide **reimbursement for diagnosis and treatment and funding for research**. Reallocation within the Academic Component should be as follows: **80% is destined for diagnosis and treatment and 20% for research and innovation.**
- **Reimbursement of the more standardised top ranking specialist healthcare** (as mentioned in the government's policy statement of September 2010) is consolidated through healthcare premiums.
- One aspect is of particular importance. **Reimbursement of orphan drugs** administered within a hospital-care setting can only be claimed by designated centres of expertise (in practice these are the university medical centres).

PORTUGAL

National Programme for Rare Diseases 2008-2015

- The **Directorate General of Health**, together with the Office of the High Commissioner for Health, have co-funded**, a total amount of € 1.9 million**, during the years of 2008 to 2011, a **few projects on rare diseases**, which are currently being developed by several patient associations, which enabled the implementation of some actions mentioned in the National Plan.

ROMANIA

Romanian National Plan for Rare Diseases 2010-2014 (draft)

- **Funding will be provided for the reference/competency/county medical centers**,
- **Funding will be ensured from various sources**: payment for certain services, national programs, education or expertise activities, epidemiologic studies, etc.
- Constant **financial support of labs for the molecular testing of rare diseases with state budget funds or various sponsorships** in order to improve the genetic testing.
- Identification of potential partners in the implementation of projects with internal or external funding, counseling for those willing to apply to national/international grants/funding programs.
- Organizing training courses on project writing, counseling for accessing national and European funding.

SLOVAK REPUBLIC

Slovak National Strategy for the Development of Health Care for Patients with Rare Diseases 2012-2013

- The diagnostic process of many RD is usually multistage and time-consuming and demanding on the expertise of highly educated specialists. The treatment of some RD is expensive. **There is no available data about the costs related with the treatment of RD**.

- **It is not currently possible to estimate a medium-term prognosis of the costs for the improvement of health care for RD patients**. These calculations will be available only based on the MKCH-10 statistics, which will include all RD.

SLOVENIA

Work Plan for the Field of Rare Diseases in the Republic of Slovenia (2011)

The Work Plan will be drafted for the period up to 2020 and will serve as a starting point for the preparation of annual action plans.

Among the planned activities:

- To form guidelines for the placement of drugs for rare diseases in programmes of compulsory or supplementary health insurance, and to **study the option of acquiring additional sources for funding very expensive drugs**.
- The **possibility of financing development and research**, and above all, useful projects in the field of rare diseases has to be envisaged.
- **To dedicate funds to development and useful research projects** in the field of rare diseases.

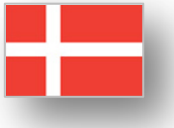
SPAIN

Rare Diseases Strategy of the National Health System (2009)

- **The strategy for rare diseases as well as any other related measures or actions aimed at rare diseases are included in the Spanish National Health Budget**.
- Given the decentralised health administration of Spain in Autonomous Communities, the Strategy will act as a framework and a set of recommendations for the different regions, which will in turn be in charge of implementation.
- The **Ministry of Health, Social Services and Equality uses the *Funds for the Implementation of Health Strategies*** in particular*:* **these funds are used by the Autonomous Communities to implement the Rare Diseases Strategy of the Spanish National Health System**.

- E-RARE
- IRDiRC : National registry, specific research projects

Other Countries…



DENMARK

The Strategy should be adopted in autumn 2013. It is expected that it will not have a dedicated budget, although some recommendations could be funded within the general budget.

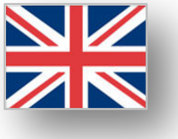
IRELAND

- Consultation on the Irish National Plan for Rare Diseases

Negotiations are ongoing: currently, no specific budget seems to be allocated to the draft Plan

LUXEMBOURG

- Les maladies rares: Enquête sur la situation des personnes atteintes de maladies rares au Grand-Duché de Luxembourg 2011



UNITED KINGDOM

- Consultation on the United Kingdom Plan for Rare Diseases
- Equality Analysis: UK Plan for Rare Diseases

Negotiations are ongoing, with adoption expected by the end of 2013: at present, it seems unlikely that there will be a dedicated budget for the plan

RD National Plans/Strategies
AT A GLANCE

News

EURORDIS Membership Meeting 2013
30 May - 1 June 2013
Hotel Rixos Libertas, Dubrovnik - Croatia
[visit the website]

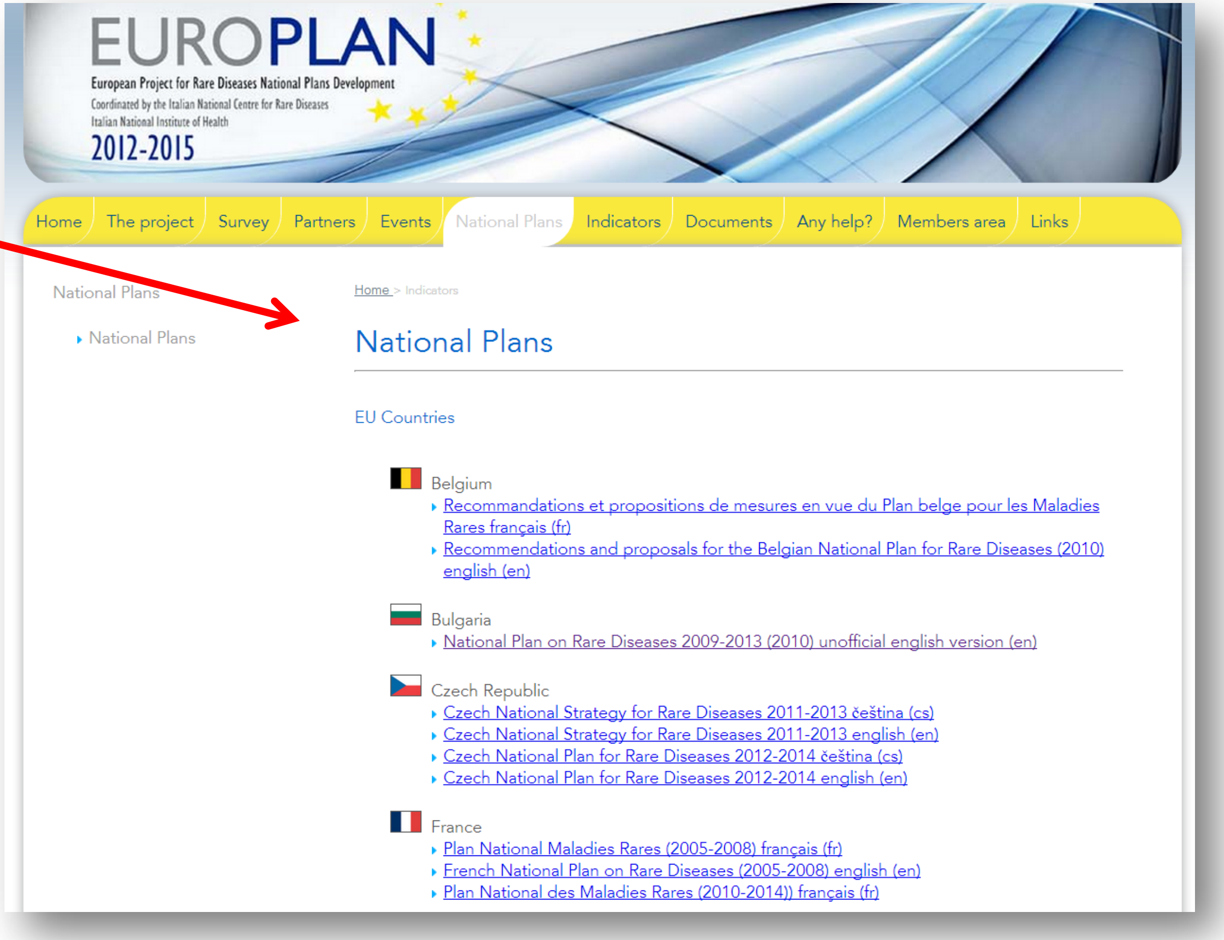
International Summer School "Clinical practice guidelines on rare diseases"
8-12 July 2013
National Institute of Health, Rome - Italy
[visit the website]

International Summer School "Rare Disease and orphan drug registries"
16-20 September 2013
National Institute of Health, Rome - Italy
Deadline for application submission: 30 June 2013
[visit the website]

2nd Edition of the International Workshop "Rare Disease and Orphan Drug Registries"
21-22 October 2013
National Institute of Health, Rome - Italy
[visit the website]

EUROPLAN 2012-2015. All rights reserved | Contact | europlan@iss.it

RD National Plans/Strategies
AT A GLANCE



EUROPLAN
European Project for Rare Diseases National Plans Development
Coordinated by the Italian National Centre for Rare Diseases
Italian National Institute of Health
2012-2015

National Plans

- National Plans

Home > Indicators

National Plans

EU Countries

Belgium
- Recommandations et propositions de mesures en vue du Plan belge pour les Maladies Rares français (fr)
- Recommendations and proposals for the Belgian National Plan for Rare Diseases (2010) english (en)

Bulgaria
- National Plan on Rare Diseases 2009-2013 (2010) unofficial english version (en)

Czech Republic
- Czech National Strategy for Rare Diseases 2011-2013 čeština (cs)
- Czech National Strategy for Rare Diseases 2011-2013 english (en)
- Czech National Plan for Rare Diseases 2012-2014 čeština (cs)
- Czech National Plan for Rare Diseases 2012-2014 english (en)

France
- Plan National Maladies Rares (2005-2008) français (fr)
- French National Plan on Rare Diseases (2005-2008) english (en)
- Plan National des Maladies Rares (2010-2014)) français (fr)

RD National Plans/Strategies *AT A GLANCE*

BELGIUM

- Recommandations et propositions de mesures en vue du Plan belge pour les Maladies Rares français (fr)
- Recommendations and proposals for the Belgian National Plan for Rare Diseases (2010) english (en)

BULGARIA

- National Plan on Rare Diseases 2009-2013 (2010) unofficial english version (en)

CZECH REPUBLIC

- Czech National Strategy for Rare Diseases 2011-2013 čeština (cs)
- Czech National Strategy for Rare Diseases 2011-2013 english (en)
- Czech National Plan for Rare Diseases 2012-2014 čeština (cs)
- Czech National Plan for Rare Diseases 2012-2014 english (en)

FRANCE

- Plan National Maladies Rares (2005-2008) français (fr)
- French National Plan on Rare Diseases (2005-2008) english (en)
- Plan National des Maladies Rares (2010-2014)) français (fr)

GERMANY

- Maßnahmen zur Verbesserung der gesundheitlichen Situation von Menschen mit Seltenen Erkrankungen in Deutschland (Measures to improve the health situation of persons with rare diseases in Germany) Deutsch (d)

RD National Plans/Strategies
AT A GLANCE

GREECE

- Greek National Plan on Rare Diseases 2008-2012 greek (gr)

IRELAND

- Consultation on the Irish National Plan for Rare Diseases english (en)

ITALY

- Consultation on the Italian National Plan for Rare Diseases italian (it)
- Italian National Plan for Rare Diseases 2013-2016 (Draft) italian (it)

LUXEMBOURG

- Les maladies rares: Enquête sur la situation des personnes atteintes de maladies rares au Grand-Duché de Luxembourg 2011 français (fr)

NETHERLANDS

- Strategy of The Netherlands in the field of Rare Diseases (draft) english (en)
- Concept Nationaal Plan Zeldzame Ziekten netherlands (nl)
- Nationaal Plan Zeldzame Ziekten - Official site with information concerning the elaboration of a National Plan for RD in the Netherlands (nl)

RD National Plans/Strategies *AT A GLANCE*

PORTUGAL

- Programa Nacional para Doenças Raras / National Programme for Rare Diseases 2008-2015 portuguese (p)

ROMANIA

- Romanian National Plan for Rare Diseases 2010-2014 (Draft) romanian (r)
- Romanian National Plan for Rare Diseases 2010-2014 (Draft) english (en)

SLOVAK REPUBLIC

- Slovak National Strategy for the Development of Health Care for Patients with Rare Diseases 2012-2013 slovak (sk)
- Slovak National Strategy for the Development of Health Care for Patients with Rare Diseases 2012-2013 english (en)

SLOVENIA

- Work Plan for the Field of Rare Diseases in the Republic of Slovenia slovene (sl)
- Work Plan for the Field of Rare Diseases in the Republic of Slovenia english (en)

SPAIN

- Estrategia en Enfermedades Raras del Sistema Nacional de Salud / Rare Diseases Strategy of the National Health System spanish (e)
- Estrategia en Enfermedades Raras del Sistema Nacional de Salud / Rare Diseases Strategy of the National Health System english (en)

UNITED KINGDOM

- Department of Health website - Consultation on the UK Plan for rare diseases english (en)
- Consultation on the United Kingdom Plan for Rare Diseases english (en)
- Equality Analysis: UK Planfor Rare Diseases english(en)

EURORDIS
Rare Diseases Europe

Membership Meeting 2013

DUBROVNIK

30 May - 1 June

In collaboration with:

Croatian Alliance for Rare Diseases

Co-funded by
the Health Programme
of the European Union

With the support of:

AFMTÉLÉTHON
INNOVER POUR GUERIR

ALEXION
BAYER
biogen idec
BIOMARIN
BioMarin Europe Ltd.
Celgene
Chiesi
People and ideas for innovation in healthcare
CSL Behring
Biotherapies for Life™
genzyme
A SANOFI COMPANY
gsk GlaxoSmithKline
Rare Diseases
ORPHAN EUROPE
RECORDATI GROUP
Pfizer
Shire
sobi

Italian National Centre for Rare Diseases - Italian National Institute of Health - Rome (Italy)

2012-2015