



**EUROPLAN PROJECT  
NATIONAL CONFERENCE ON RARE DISEASES**

**WORKSHOP  
SUSTAINABILITY  
OF INFRASTRUCTURES AND ACTIVITIES  
IN THE FIELD OF RARE DISEASES**



**RELEVANT EXTRACT FROM THE  
EUROPEAN COUNCIL RECOMMENDATIONS  
ON ACTIONS IN THE FIELD OF RARE DISEASES**

**LUXEMBOURG, 9 June 2009**

# COUNCIL RECOMMENDATIONS

**“HEREBY RECOMMENDS that Member States:**

**Together with the Commission, aim to ensure, through appropriate funding and cooperation mechanisms, the long-term sustainability of infrastructures developed in the field of information, research and healthcare for rare diseases.”**



**RELEVANT EXTRACT FROM THE  
SPECIFIC EUROPLAN RECOMMENDATIONS  
FOR THE DEVELOPMENT OF NATIONAL PLANS  
FOR RARE DISEASES**

# EUROPLAN RECOMMENDATIONS

- The National Plan or Strategy on rare diseases is supported according to the Country health system and decision-making processes
- Possibilities for European funding are exploited for National Plans or Strategies for rare diseases
- The cooperation with other member states is envisaged in order to address the need for sustainability of common European infrastructures, share costs and maximise the efficacy of initiatives
- Participation in the debate on enhanced EU governance is ensured, in order to find agreed and improved mechanisms for the governance of the healthcare, information and research initiatives requiring transnational collaboration
- Agreements for coordinated projects, including long-term sustainability of common infrastructures, are pursued within the framework of the open method of coordination among member states



**RELEVANT EXTRACT FROM THE  
EUROPLAN INDICATORS  
TO EVALUATE THE ACHIEVEMENTS OF RD INITIATIVES**

# EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
<p>Ensure through appropriate funding mechanisms the <b>long-term sustainability of infrastructures</b> developed in the field of:</p> <ul style="list-style-type: none"> <li>- information</li> <li>- research</li> <li>- Healthcare</li> </ul>	<p>Existing policy/decision to ensure long-term sustainability of the RD plan /strategy</p>	<p><b>Process</b></p>	<p>Yes Not</p>
	<p>Amount of funds allocated for ensuring RD plan /strategy sustainability</p>	<p><b>Outcomes</b></p>	<p>Millions of Euros invested per year</p>

# EUROPLAN INDICATORS

ACTIONS	INDICATORS	TYPE	ANSWERS
<p>Cooperate with other Member States to address the <b>need for sustainability of European-wide research infrastructures</b>, common to all Member States and common to the highest possible number of rare diseases</p>	<p>Existing policy/decision to ensure the contribution to support RD European infrastructures</p>	<p><b>Process</b></p>	<p>Not existing, not clearly stated</p> <p>Existing, clearly stated, partly implemented and enforced</p> <p>Existing, clearly stated and substantially implemented and enforced</p>





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**FURTHER GUIDELINES FOR DISCUSSION**

# SUSTAINABILITY OF A NATIONAL PLAN

- Is there a specific budget attached to the National Plan?  
Does it ensure the long term sustainability of its actions?
- What are the main sources of funding of the National Plan?
- Are there specific budget provisions accompanying specific actions in certain priority areas e.g. orphan drugs, Centres of Expertise, diagnosis, research, etc.?

# SUSTAINABILITY OF INVENTORIES, REGISTRIES AND LISTS

- Do these registries and programmes receive government support?
- How to ensure, through appropriate funding mechanisms, the long-term sustainability of registries and databases?

# SUSTAINABILITY OF RESEARCH

- How to ensure, through appropriate funding mechanisms, structural and long-term sustainability of research projects and research infrastructures in the field of Rare Diseases?

In particular in respect of public health and social research, as well as transversal infrastructures.

# SUSTAINABILITY OF CENTRES OF EXPERTISE

- How to ensure, through appropriate funding mechanisms, the long-term sustainability of healthcare infrastructures, in particular Centres of Expertise?

# SUSTAINABILITY OF SPECIALISED SERVICES

- **RESPITE CARE SERVICES**
- **THERAPEUTIC RECREATIONAL PROGRAMMES**
- **SERVICES AIMED AT THE INTEGRATION OF PATIENTS IN DAILY LIFE**
  - How are specialised services financed?
  - By the government institutions and budget?
  - By private initiative?
  - By patient associations?

# SUSTAINABILITY OF HELP LINES

- How are help lines financed?
- By private initiative or patient associations?
- Is there any government funding?
- How to ensure their long-term sustainability?

# INVOLVEMENT OF PATIENTS

- How to ensure, through appropriate funding mechanisms, patient representativeness in decision-making processes relevant to Rare Diseases?



# INFORMATION SHARING

How to improve information on available care for rare diseases in general, for different audiences?

- Do the following initiatives receive public funding / are they mainly promoted and funded by patient associations:
  - National official website for rare diseases in your country
  - Helplines for both patients and healthcare professionals
  - Programmes to stimulate the development of information and educational material for patients or specific publics (teacher, social workers, etc.);
  - Raising awareness of rare diseases, Rare Disease Day
- Are existing resources at EU level used?



**SUSTAINABILITY  
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PROPOSALS FROM THE AUDIENCE**